UNDERSTANDING BARRIERS TO ACCESS FOR WOMEN WITH CANCERS IN EAST AFRICA

A Thesis

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Masters of Science

By

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ABSTRACT

Background

In low and middle incomes, the majority of patients are diagnosed with advanced cancers (stage III and IV) which results in more cancer deaths. Even after a diagnosis of breast cancer, many patients do not complete their treatment. The reasons why delays in diagnosis and treatment occur are multilevel, involving a combination of patient, financial and system-related factors. Sociocultural factors such as stigma may also play a role.

Methods

For Chapter 1, we examined the experience of women with breast cancer in East Africa. (Kenya and Tanzania). We carried out a qualitative study using in depth interviews to describe the experience of women with breast cancer and to describe the barriers and facilitators to care for women in this region. Women who had completed at least a year of treatment were eligible to participate and 28 ladies shared their experiences. For Chapter 2, we performed a systematic review to determine the role of stigma as a barrier to care for breast cancer diagnosis, treatment and follow up.

Results

In Chapter 1**,** 28 women were interviewed in Kenya and Tanzania. For patients who completed a year of treatment, the cost of treatment and expenses incurred was a major concern. Family disintegration emerged as a significant theme following cancer

diagnosis. There was a prevalence of stigma around breast cancer and patients would not disclose their status to others in the community for fear of being ridiculed, pitied or isolated. A number of patients used alternative medicine resulting in delays in treatment. Family support, support groups and spirituality played a major role in facilitating the completion of initial care and in reducing psychological morbidity. System factors such as poor referral pathways, and inappropriate treatment emerged as minor themes.

In Chapter 2, 2372 articles were identified, 202 full text reviews performed and data extraction done on 38 studies from Africa and Asia. Anticipated stigma (21/38 studies,55.3%, CI, 38.3 -71.4%) and perceived stigma (21/38 studies,55.3%, CI 38.3 - 71.4%) were the highest reported. Thirty five out of thirty-eight studies, (92.1%, CI 78.6-93%), mentioned other socio-cultural factors. The sociocultural factors mentioned in decreasing frequency were a) fatalism (65%), b) myths around breast cancer (47.4%), c) fear of surgery (39.5%) d) conservatism (34.2%), e) use of alternative medicine (28.9%) f) spirituality/religion as a barrier (23.7%) and g) collectivism. Studies that had perceived stigma had higher rates of alternative medicine use (48%, 10/21) than studies that did not have perceived stigma (6%, 1/17). No other significant differences were found between studies that had perceived stigma and those that did not (p=0.21->0.95). No other significant associations were found between stigma, sociocultural factors, region or groups studied

Conclusions

The sociocultural aspects of breast cancer need to be addressed in order to ensure comprehensive management of breast cancer patients and completion of

treatment. As programs in the region, mainly run by governments, aim to improve the financial access to treatment, it would be critical to include efforts aimed at stigma reduction and interventions focusing on the sociocultural re-integration of these patients.

BIOGRAPHICAL SKETCH

Career goal: to become an independently funded clinical investigator in the field of addressing disparities in breast cancer management in low and middle-income settings and in designing interventions that address barriers to care in this region.

Miriam Mutebi is a Consultant Breast Surgical Oncologist based at the Aga Khan University, Nairobi. She did her general surgery residency at the Aga Khan University Hospital in Nairobi, Kenya. She subsequently did a two-year fellowship in Breast Surgical Oncology, which included a year in the plastics and reconstruction unit at the University of Cape Town, Groote Schuur Hospital in South Africa. She then worked as a surgical oncology research fellow doing studies on the quality of life of breast cancer survivors in the Western Cape, and briefly at the Memorial Sloan Kettering Cancer Centre as a recipient of the Mammadi Soudavar Fellowship. She also works currently as a Surgical Oncology Research fellow at Memorial.

As a cancer surgeon, she has a keen research interest in understanding the barriers to the diagnosis and treatment, for women with cancers in East Africa. She is completing her training in Clinical Epidemiology and Health Systems Research at the Weill Cornell University and her focus lies in understanding these barriers and in designing interventions to mitigate the barriers. She has led projects training health

workers in knowledge and practical skills in breast health awareness and in clinical breast exam, and trains cancer advocates in both Kenya and South Africa.

She is the new African Regional Lead for the Union for International Cancer Control (UICC) and a member of the Education and Training committee of the African Organisation for Research and Training in Cancer (AORTIC). She is also the co-founder of the Pan African Women's Association of Surgeons that aims to provide mentorship for women in surgery, and to improve women's health and surgical care on the continent.

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CHAPTER ONE

Understanding the experience of women with breast cancer in East Africa: A qualitative study in Kenya and Tanzania

ABSTRACT

BACKGROUND

Breast cancer is one of the leading causes of premature death in women in East Africa. The majority of patients are diagnosed with advanced cancers (stage III and IV) which results in more cancer deaths. Even after a diagnosis of breast cancer, many patients do not complete their treatment. The reasons why delays in diagnosis and treatment occur are multilevel, involving a combination of both patient related and financial factors and system related factors. The aim of the study was to understand the experience of breast cancer patients in East Africa, in order to determine the facilitators and barriers to diagnosis, treatment and follow up of breast cancer.

METHODS

28 patients in Kenya and Tanzania who had completed at least a year of initial treatment were invited to participate in the study. A qualitative exploratory study was done using semi structured, in depth interviews. Grounded theory was then used to analyse and develop themes that emerged from these narratives.

RESULTS

For these patients who completed a year of treatment, the cost of treatment and expenses incurred was a major concern. Family disintegration emerged as a significant theme following cancer diagnosis. There was a prevalence of stigma around breast cancer and patients would not disclose their status to others in the community for fear of being ridiculed, pitied or isolated. A number of patients used alternative medicine

resulting in delays in treatment. Family support, support groups and spirituality played a major role in facilitating the completion of initial care and in reducing psychological morbidity. System factors such as poor referral pathways, and inappropriate treatment emerged as minor themes.

CONCLUSIONS

The sociocultural aspects of breast cancer need to be addressed in order to ensure comprehensive management of breast cancer patients and completion of treatment. As programs in the region, mainly run by governments, aim to improve the financial access to treatment, it would be critical to include efforts aimed at stigma reduction and interventions focusing on the sociocultural re-integration of these patients.

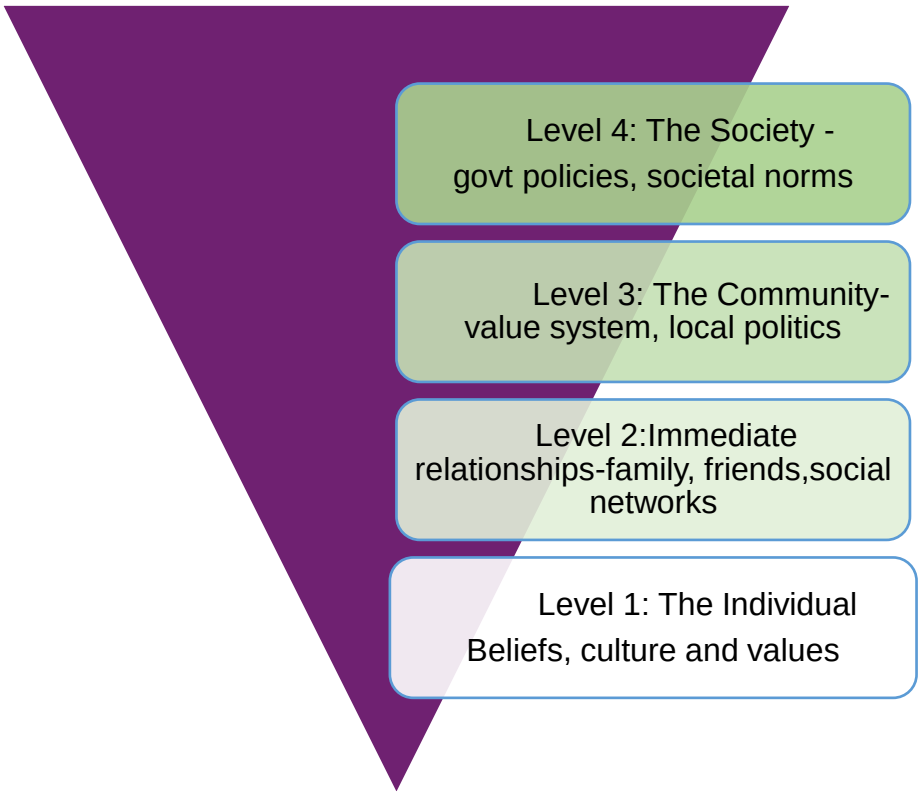
Introduction

Cancer has become a major public health issue in low- and middle-income countries (LMIC). By 2020, WHO project that 70% of the 15 million new annual cancer cases world-wide will be in developing countries. (ref) This is in contrast to only 15% of global cancers recorded from developing countries in 1970. (1) While incidence to mortality ratios are low in developed countries, (46%), low income countries have incidence to mortality ratios as high as 75% (2).

Similar trends are seen in breast cancer, which is one of the most common cancers affecting women in East Africa. Lack of resources and trained health personnel result in African women not having access to cancer screening and early diagnosis. The rising incidence of breast cancer in countries with limited resources requires a paradigm shift to view cancer as a public health problem with serious cost implications and poor outcomes if not prevented or detected early(3).

In sub Saharan Africa breast cancer patients are 10-15 years younger than their western counterparts (4) and the majority are diagnosed with advanced (stage 3 and 4) disease (5,6,7,8,9). The reasons behind this are numerous. The socioecological model (10) may serve as framework to explain the different factors that influence health seeking behaviour of an individual and the levels at which different barriers to care may exist. These levels may also serve as loci for interventions to improve these barriers. Indeed, successful intervention strategies involve multilevel consideration of all these aspects. (Figure 1.1)

FIGURE 1.1: THE SOCIO-ECOLOGICAL MODEL AS ADAPTED TO CANCER CARE AND CONTROL



The model serves to explain how an individual's health has multilayered areas and successful interventions require consideration at each of these levels

There is little in the literature describing the breast cancer experience of patients in East Africa. A recent qualitative study in Uganda describes stigma as a significant factor preventing engagement with the health system for breast cancer patients (11).

Whether similar themes come into play in Kenyan and Tanzania setting, is largely unknown. The aim of this study was to gain an in-depth understanding of breast cancer patients' experiences and to explore barriers and facilitators in accessing breast cancer diagnosis, treatment and subsequent follow up.

Methods

Study Setting:

Interviews were conducted at two private hospital and one public hospital in East Africa. The Aga Khan University hospital Nairobi, Kenya and the Aga Khan Hospital, Dar es Salaam, Tanzania act as tertiary referral centres for oncology patients in the region who can afford private care. Interviews were also conducted at the Ocean Road Cancer Centre, in Dar es Salaam, Tanzania. This is the national public tertiary referral hospital for oncology services in Tanzania. The Ocean Road cancer centre caters to mainly underserved patients in Tanzania

Eligibility criteria

Patients had to be female, over eighteen years (legal consent age in East Africa) and fluent in Swahili or English, which are the national languages spoken in these two countries. Patients who could not speak Swahili or English were ineligible for the study. Patients who were too unwell to participate in an interview were excluded from the study. Patients with a histological diagnosis of breast cancer who had completed at least a year of initial treatment were invited to participate in this study. Any breast cancer patient attending the clinic for follow up visits at the Aga khan Nairobi, Dar es

salaam, The Ocean Road Cancer institute or any support groups near these facilities was invited to participate in the study. Depending on the stage of the disease, patients needed to have completed a year of therapy, which may have included surgery, chemotherapy or radiation therapy in different combinations.

Methodology

Women meeting the eligibility criteria were invited to participate in the study. Patients were identified at the clinics at these institutions or at affiliated support groups at the different facilities. The primary mode of recruitment was through purposive sampling of clinic attendees. A few patients were also identified through a snowballing technique. This is where patients are asked to make recommendations about other patients who might be interested in participating in the study.

An interview guide was developed (appendix 1) and semi-structured in-depth interviews with breast cancer survivors were conducted to determine common themes. The questions were designed to explore women's breast cancer experience from diagnosis, management and on to survivorship. They explored patient's support systems and coping mechanisms. Barriers or facilitators to their care were examined. Their follow up and current functioning was elicited along with their perceptions of the health system and health workers.

Conduct of Interviews

Interviews were conducted in person in a comfortable private setting with the primary interviewer and a bilingual research assistant. The patient was assured of

confidentiality and invited to share her candid views on her experience. An audio recording was transcribed. Recordings done in Swahili were translated by a trained translator to English.

Qualitative Analysis

The interviews were transcribed verbatim and interviews done in Swahili were translated into English by a trained professional transcriber and translator. Interviews were analysed concurrently with data collection, and triangulation was done to enhance understanding of some emerging themes.

Line by line coding was performed and analysis was done through comparison of transcripts after reading and rereading transcripts. Using data software Atlas ti, data analysis was done using initial open coding to identify concepts. Data coded using the line-by-line approach, was then used to develop an initial conceptual framework around breast cancer survivors' and their experiences of management and survivorship. The primary unit of analysis was the breast cancer survivor and the focus was on her experiences of cancer diagnosis and treatment. Secondary units of analysis were the facilitators and barriers to care and follow up adherence and patient's perceptions of health workers and the health system. The number of items generated from a code were explored. Each code was examined to generate an initial item that was assigned a descriptor. It was found that a single code could generate more than one item. However, if the patient repeated the same phrases more than once in her interview, it was regarded as the same item, as the concept had been expressed. Axial coding was done to determine the categories and selective coding was done to develop the themes

that emerge. Two coders did the coding independently. The results were then compared and consensus was obtained.

Through a collaborative process, the two researchers independently reviewed each transcript and reflected on the themes that emerged. The team then meet to discuss what they felt the emergent themes were. After several iterations of this process, a code book was developed and used for the subsequent analysis. After the initial coding, categories were developed and then subsequently grouped into themes. This coding was done through an iterative process of reading and rereading transcripts. Peer checking was done to confirm the agreement of the results obtained by the team. Cases of disagreement were resolved through discussion.

RESULTS

28 women were interviewed. The interviews lasted approximately 30-45 minutes. The median age of women interviewed was 46, (range 31-72). All patients had completed at least a year of treatment with years after treatment ranging from 2 years to 12 years. Many patients were unaware of the stage of their disease (with no confirmatory records present) but all patients had surgery and chemotherapy. Most patients had a mastectomy and one patient had breast conservation surgery and one patient had a delayed reconstruction after mastectomy.

Barriers to care

There were multiple barriers to seeking hospital treatment that emerged.

1) Health System and Financial Barriers (Table 1)

A) Lack of access to health care. (Table 1)

TABLE 1.1: RESULTS OF BARRIERS TO CARE

THEMES	**QUOTE**
1.Lack of Access to care: Subtheme: accessibility to health workers	*'As time went by, I have come about 2 or 3 times, in this room. It is as if the doctors were not there that day, in the clinic. We had to go and look for other doctors to help us.'PP23* *'Because there are many patients, and someone cannot attend to everyone as they would like, they must attend to them as they can. So the services are going well' PP25*
Lack of Access to care: Subtheme: Transportation	'*The first challenge is transportation. The hospital is in the village and there is no car which goes all the way there. If you want to get to Ocean Road you must take a private vehicle to get you here. The first challenge is transportation, the means to get to the hospital'* PP20 *'I was to come on 25th, but because I lacked fare, I delayed in coming. I stayed for 3 months. Right now, because they told me there is a lump on my chest and I need to go for chemo*.' PP22
Lack of Access to care: Subtheme: Non availability of drugs/Facilities	*And at that time, medicine was not available here. We had to buy it. I think it was not after so many doses, I don't know, that the medicine was available'* PP23 *'Other times, medicine, when you get to the pharmacy, when you get to the window you are told this medicine is not there, go to insurance'* PP23. *'What I found challenging was the availability of chemotherapy drugs. But I got a lot of support, so the drugs would be there, although sometimes you*

TABLE 1: Barriers cont.,	*would be told that they are not there, but after a while they are found so you continue'* '*I think so. And then there's only one machine. When it gets spoilt, people are told it is not working and needs to be repaired, and so you are sent away. That is also a challenge'* PP21 '*When it came to radiotherapy it was difficult because there are many patients. You can go there in the morning and get treatment after a long time since there is only one machine. And sometimes it gets spoilt. So, you just have to be patient to until you finish'* PP26
2.Financial Burden of disease	*So the challenge came about from not having health insurance. So it means, while undergoing treatment, everything required money' PP28* *'And when you see the situation, has become challenging. Cost of living is challenging, even finding that money.' PP24* *'When you get to insurance, you are told the medicine is being sold at tsh 100,000 or tsh 150,000 to tsh 200,000. And you don't have the money. How do you treat yourself?' PP20*
3.System Barriers: Sub Theme. Healthworker misinformation	*After delivering, I noticed the lump growing and felt some pain. I went to hospital and explained myself. I was told, it is possible it is a boil. Continue breastfeeding. Don't be afraid. So I continued breastfeeding till the age he stopped. When I stopped the lump did not go. I continued waiting'* PP08

Table 1: Barriers cont.,	
System Barriers: Sub theme. Health system inefficiencies	*What happened is that after they tested, the doctor sent me back to them to test whether I am not positive. Whether the tumour was something positive or negative. And I don't know whether they had thrown away the sample or something, he was very hostile. Up to date I don't know whether I am positive or what*.' PP 07 '*So, I came for a blood test, then went to Room no. 1 and our names called out twice, my name was not one of them. I was told, go back to the laboratory. I went there and they could not find my results. They checked elsewhere and could not find it. They told me, let us test you again*' PP23 *'I told her, they claimed that they do not have the results from the sample that was taken to "Muhimbili". Every time I go, I am told to return on a certain date. Till the day I went there last, they suggested I undergo another operation'* PP23
System Barriers: Sub theme. Health worker Negativity	*Somewhere else, not in Aga Khan. But there is a doctor who asked me, why are you wasting your time? You are at stage 4, late, why are you wasting your time?'* PP08

This was reflected in the lack of both physical and human resources that were available to patients. In the public health system, patients reported lack of availability of doctors to cater to them. The participants (PP) noted that when doctors were available,

they were frequently few and having to attend to many patients (PP023, PP025). Access to tertiary referral centers was also over long distances and participants noted that the costs to reach the tertiary health facility were great (PP020, PP022). Access to radiotherapy and chemotherapeutic agents and other medication was also noted to be a challenge in this setting. Participants frequently had to pay out of pocket for medication that was not available in the institution (PP023, PP21, PP26).

B) Financial burden of cancer. (Table 1)

The cost implications of treatment were a dominant theme among participants interviewed. This frequently related to patients having to pay largely out of pocket to finance their treatment. There were high costs of medication and treatment with many people not having health insurance and having to rely on family and friends to support their treatment (PP020, PP024, PP028).

C) System barriers to care. (Table 1)

Delays in diagnosis, misdiagnosis or inappropriate assurances resulted in delays in patients receiving the care they needed. On reporting a lump, some participants were either given medication like antibiotics or as in the case of one lactating mother, who was simply asked to just continue breastfeeding (PP08). Inefficiencies in systems and poor referral pathways from initial providers played a role in delaying treatment. Participants had their samples discarded (PP07) or had missing test results (PP023). One participant was asked to return to the lab, a long distance from her home several times until personnel finally admitted that they had misplaced her histology results

(PP023). Perceptions of health workers could also influence patient's outlook and willingness to receive treatment. In some instances, participants with advanced disease were discouraged from getting treatment for their cancer (PP08).

2) Patient mediated barriers

A) Negative family influence and socio-cultural barriers to care. (Table 1.2)

Socio-cultural factors had a huge influence on the breast cancer patients. Negative perceptions of treatment weighed on patients and acted as a source of discouragement. Sociocultural factors included fatalism, myths around cancer and its treatment and social stigma. All these caused considerable distress amongst patients. Patients were discouraged from receiving treatment (PP024) or told that treatment would have grave consequences to them including death (PP25).

TABLE 1.2: NEGATIVE FAMILY INFLUENCE AND SOCIOCULTURAL BARRIERS TO CARE

THEME	**QUOTES**
Sociocultural barriers **Subtheme: Negative family influence**	'*Yes. Even my husband also told me not to go to hospital, you will die'* PP24 '*Coming here, people say, radiation burns, radiation has this, radiation kills*' PP25
Sociocultural barriers **Subtheme: Fatalism**	'*Many of them discouraged me by telling me that cancer has no treatment. So you are a corpse-in-waiting. And it reached a point at my workplace, there was one colleague who died. Many people thought it was me who had died. So the discouraging bit is when people tell you there's no cure for this, people believe*

TABLE 1.2 sociocultural barriers cont.,	*that cancer cannot be cured. Once you have it, you just die.' PP19* *'There are those who take the problem like, ah, this one ,Let us just sit with this one…but we can bury her at any time'* PP22
Sociocultural barriers **Subtheme: Myths around cancer**	*'That one, some say I got it sexually. It is sexually transmitted. That is not the case. It is a normal disease that has been sent by the devil, or by God, we don't know. Because it affects the small, the big, the old, the young'* PP21
Sociocultural barriers **Subtheme: Stigma**	*'Yeah when I went back to work, it was like, oh she can't do this. I said, why? Give me something and we see if I can't deliver. But my immediate boss was like, no. Even when the project was over, actually she signed and said, no, we don't want XXX in the next project. Because maybe she will again fall sick and we are, you know, that kind of thing. So I missed that opportunity.... So there is that kind of stigmatization....PP15* *The emotions come to mind why I'm like this? Now I have two breasts, now I have one. I lost one breast. I don't know what the people saying about me, how they feel. My relatives start to see me like something not good. I feel so bad because I was not getting any encouragement from the family. Instead of family say, Ah! Why you are like this? You lost one breast, now see how you are looking. I feel very bad. Every time I was anxious. They didn't give me even the word for…for comfort my heart. I feel very bad. PP02*

Cont., Sociocultural barriers **Subtheme: Stigma**	*Because when someone saw me it's as if they were pointing a finger at me, saying this woman does not have a breast. I didn't like sitting, in the evenings we usually sit with my husband. In the evenings, we have a grocery at home, we sit there and chat and customers drink. But after the operation, I didn't want to because when they came they would know I did not have a breast. It bothered me a bit. Also some time when I saw people talking, I would think they are talking about me not having a breast. So it bothered me. PP04* *….here the awareness is low. That is why when we come for cancer support groups for so many weeks, there are people who have not even told their mothers…..They have not told her because of how she will receive the news. The education is not good. Still, people here, when someone hears, they only see death. And I hear many of them when they talk, when they are discussing someone. Even others, when we are together, they say, so and so has cancer. They just explain as if someone is dying. But I can't tell them that I also have that problem. Mostly I just comment, that we need to check our health….Like in my case, very few people know I have cancer.PP013*
Sociocultural barriers **Subtheme: Family disintegration**	*Q: Are you married?* *A: I'm married but when I had this thing, my husband says because they will take away the breast, I am no longer with you. (cries) PP02* *..There were so many challenges. One, coping with a new born baby and then the worst part is that before I could even recover fully, my family broke down, that was the most challenging thing…..My family just broke down, and we thought it is the end of it all and it's in my opinion when cancer catches up with a young couple, the other person should be part of, should be a patient also, should be a patient. Actually it shouldn't*

Cont., **Sociocultural barriers** **Subtheme: Family disintegration**	*be a voluntary thing it should be part of, because I think he feared, he thought I would die, and look for another lady to bring up the children, you know, that was the talk at least. Like you know, him he could see death and so as much as I was sick, I think in my opinion today, he was more sick then me. PP07* *The hindrance maybe is my husband…* *He thinks it is a normal disease. Then he despises me. Because you can't go to theatre, cut a part of your body, then you hear your partner telling you, you are pretending, so that your brothers can sympathize. You are pretending, neither are you in pain. How would you feel? If you go to theatre, do you really pretend? Does sickness pretend? And I wanted to make a step so that my children can carry their mother, what can they do? But now they find I've sunk low, so he disrespects you.PP05*
Lack of awareness of disease	*"It was 1993, when I found a lump on my right breast but I didn't recognize it as a disease'* PP24 *'I didn't know these were the results and they were bad.'* PP08
Alternative Medicine	*I was told to eat a lot of carrot, a lot of leafy vegetables, pawpaw, staple food, and take the liquid from boiled cabbage, as well as the juice from boiled pepper, after washing and boiling, I drink the juice and 'mabuyu' (local seeds from baobab) PP03* *I have now I started to have you know, some leaves they told me it is a herbal leaf, these leaves are very sour, so I am taking those leaves also. And I am okay... these herbs you know they are very good leaves, you know, they are very sour. So they say sour*

Alternative **Medicine cont.,**	*is better with, because it goes with the body. So I started…. I got a car, we go and pick some, then you can, it really helps these herbs.* *Q: How did you find out about it?* *A: Somebody told me you know, they eat these, it works great you know.* *Q: So the herbs helped with the cancer?* *A: Cancer spreading yah.* *PP05* *…It wasn't easy for me to accept the chemotherapy treatment. I was doing a lot of research too, trying to understand, what it is, what are the consequences, what are the side effects? And I was kind of worried, I didn't like to go through the treatment. So I opted for alternative, kind of self-treatment with some herbalists for many years. But things wouldn't improve much until I think 2012,Or was it 2009?By then I was doing my PhD in America. I came in 2009.* PP17

ii) Fatalism. The underpinnings of these perceptions were in the fatalistic views around breast cancer. Cancer was seen by participants' families and friends as a death sentence. Participants frequently felt that those around them were just waiting for them to die (PP022).

iii) Stigma and myths around cancer. Stigma was prevalent among the participants' families with narratives around self-stigma and anticipated stigma, enacted stigma and perceived stigma being seen in participants' interactions with family and colleagues. Some of the genesis of stigma were in the myths around breast cancer. These

narratives had to do with the perceived promiscuous nature of those with cancer (PP021) or due to witchcraft. Participants faced stigma either socially or at the work place with some participants missing out on employment opportunities (PP015). Anticipated stigma was high and participants would avoid disclosure of their cancer status in order to avoid being ostracized and would only share the diagnosis with a partner or only one or two close family members. This resulted in social isolation for participants (PP04, PP13).

iv) Alternative Medicine. Participants used alternative medication to either supplement conventional treatment (PP03, PP05) or as a substitute for treatment resulting in delays in care. (PP17)

B) Family disintegration. Family disintegration following a diagnosis of cancer was common with participants noting a lack of spousal support (table 2). The immediate family was frequently the first casualty of a cancer diagnosis the lack of spousal support extended from disapproval, abuse (PP05) or abandonment (PP02, PP07).

C) Lack of awareness of disease Lack of knowledge about breast cancer resulted in some participants ignoring symptoms. Many participants were initially not aware that breast cancer was a problem and thus did not seek any medical attention for their condition (PP08, PP24).

Facilitators to Care

1. Breast awareness

Knowledge of breast cancer symptoms resulted in positive health seeking behaviour for some participants.

'Because there was a place we read and were told that if you see a lump on your body, then know it is cancer. So I asked myself and thought it is best to go to hospital' PP25.

Sometimes a family history of breast cancer would prompt this health seeking behavior.

'And because of my mother's experience who had been diagnosed in 2001, I had read a lot about cancer so I went to see a doctor' PP 07

The practice of breast self examination also raised breast awareness in this setting

'*I felt a small lump on my left breast but, which when I press it, it led to my nipple removing blood. It was small. I got shocked and went to hospital for investigations'* PP26

'I was just doing the normal checks that we had been taught how to self-check. And I realized a lump on one of my breasts for some time and then.' PP09

2. Social support structures

a) Family support. Family support was critical in helping patients complete their treatment. This support was both financial or emotional support.

'*Those who help me are my brothers and they are far. Other days, other times, you know how things are. Life is hard. Everyone has their problems. Therefore, if they can help, they help. Other times they give me bus fare to come to hospital*' PP23

'*When I went back home to tell my sister, she told me when the date reaches, we go together. We went. When we got there, she said, this lady cannot have another surgery. We do not have the results of the sample that was taken to Muhimbili. And till now, she is in pain. Give me a transfer I take her to Muhimbili*' PP23

b) Social networks–Social support structures whether it was from support from church groups, from employers, support groups or friends all played a great role in improving the outlook of the patients who completed their treatment

'*Then church groups they were always there. They used to come to my house and pray with me and then when I needed financial support, the same group, the family and the church group were the major supporters*.' PP09

'*Many times, they encourage me to have faith because there's nothing that defeats God. One day you'll be healed. There's nothing impossible with God. Follow the instructions and you'll be fine*.' PP18

'*That time I didn't even know this support group but I also met some people who had gone through cancer earlier. They just found their way to my house. So they explained to me, I learnt a lot and I can say in the beginning those people gave me more strength than anything else, because I had to tell them now show me where you were operated, I don't know why I was just not believing. But they talked to me a lot about support group, actually they were the first group to introduce me to the Kenya Breast Cancer Association'….*

'Currently I am a member of Faraja support group. That is the only group that I am in. And in that particular set-up I've been able to meet different people who've gone through the same thing. Even experienced more than I have because in the group you meet many people who have maybe had recurrent cancers once or twice and there are those who've had it even for many years than me. And so when you such people you find encouragement because they try to explain to you what they've gone through and you realize you've not even had half of what they've experienced.' PP09

c) Physician support - Physicians played an important role in encouraging patients to continue their treatment

'*The first thing that gave me the spirit to be able to go through the treatment, as I said earlier, I got a very nice oncologist. A lady, and there is this one statement that she made and it got into my head; "the doctors will only do 30%, the 70% it's you and your God. And it is all in the mind. And cancer is not a death sentence. Only you are lucky at least" and she used this statement, "You are lucky at least you got it earlier, it's not spread. So we need to do the treatment and you'll be fine." So that actually, it was like an assurance that I need to fight, I need to be positive, every step I take I am sure I am getting out of it. So that is what encouraged me.'* PP09

‘So the doctor urged me that when the wound heals, you do a mastectomy so that it does not spread. I was very sad because I had 2 small children, and I saw they were still small, I was sad but when they gave me the advice that: having cancer is not a death sentence, they took me through a seminar, I agreed with then, so I accepted the condition. I agreed and accepted.’ PP01

d) Spousal support - Spousal support was critical in helping patients achieve a positive outlook to their disease.

‘He is very much OK. First, he is very proud, he told me I'm very strong and all that. And you know something, he just looks at me as normal, like I have both breasts. It's very strange. You know it's like I'm watching a movie’. PP014

3. Access to financial resources and preparedness

Possession of health insurance and having access to a health insurance scheme was an important factor in patient’s willingness to seek care.

‘For now, I am employed. My company helps me. But the insurance caters for me because of this medicine.’ PP26

“*I said this time I met someone from the insurance. I encountered an obstacle because the cost of medication was very high beyond their capacity, so they were stuck. But I think they sorted it out later and I was able to continue with treatment.”* PP10

Access to private institutions and having funds to pay for private care reduced delays.

‘You know Nairobi hospital is a private hospital, where you pay a lot of money. So there is no delay. People who are delayed are the ones who go to public hospitals.’PP20

4. Personal factors as a coping mechanism

a) Spirituality - Many patients relied on spirituality as a way to make sense of their cancer journey and as an anchor through the challenges they faced.

"You know, when you are going through a condition like this, you really need God, it doesn't matter which religion you are. I'm not saying that I'm very good Christian than

anybody else. I'm not saying that I'm praying a lot. Some people tell me, oh you need to teach me how to pray. No. I'm only insisting that you need to look at God." PP17

b) Resilience

A positive outlook to the experience helped to facilitate completion of care for patients. Cancer was viewed as a character building event from which they emerged stronger.

*"...Looking back I think I am a better person. I am a better person because I've learnt now how to love more, to have time for everyone, to look into people and not even judge them, and I now feel like I have been given another chance by God and so I always feel like I want to go out and you know, give back to society..."*PP10

DISCUSSION

In order to understand why women in East Africa are diagnosed with advanced disease and frequently do not complete their treatment, we sought to describe the experience of women with breast cancer and identify the facilitators and barriers to care amongst women who had completed at least a year of treatment. Sociocultural barriers such as stigma, fatalism and myths around cancer were pervasive in this setting and were a considerable cause of distress for patients. Family disintegration was a major theme following a diagnosis of cancer. Financial costs and transportation were also major barriers. Facilitators to completion of care included having a comprehensive insurance plan and good social support.

Factors causing delays in care can be broadly divided into patient mediated and system mediated factors (12). Patient factors include lack of knowledge among patients, the health seeking behaviour of patients, stigma associated with a diagnosis of cancers

and a lack of financial means (12). System barriers include poor available hospital resources for the diagnosis and treatment of cancers and a lack of knowledge amongst health workers (12,13,14).

System factors

Fragmentation of care was common with many patients seeing a number of doctors before a definitive diagnosis was made. Poor referral pathways also resulted in delays in treatment. Different aspects of cancer treatment were only available at specific centres, with patients having to travel between these for their care. While this may be a reflection of the scarce resources available, the logistics of navigating these referrals, frequently over long distances, could contribute to delays in treatment. This suggests a need to decentralize care from a single source centre and move towards building regional centres of excellence.

Poor health worker knowledge or false reassurance also resulted in patient delays before a diagnosis was made. This is in keeping with finding in the continent where Price and colleagues in Cameroon found that breast cancer patients, among other patients, would see on average four health workers before being referred to appropriate oncology services (15) Many patients who could afford private treatment, consulted multiple doctors before finally seeking treatment abroad then returning home for follow up. While this may speak to a lack of available resources locally, (less so for those with private insurance), this may also reflect a deeper mistrust of health workers and systems which can only be alleviated by enhancing health worker knowledge and training in breast health.

Patient mediated Factors

Finances.

The financial burden of cancer care was a prevalent theme in our study. Our patients, like those in many parts of Africa (16), frequently had to pay out of pocket for their health expenditure. In this study, women would rely on friends or family to help them meet their treatment costs or defer treatment until funds were available. A lack of awareness of breast cancer signs and symptoms also led to delays in seeking help. A recent survey of knowledge of breast cancer amongst 225 women attending hospitals in Dar es Salaam, showed that only 30% of risk factors and 51% of breast cancer symptoms were identified correctly. (17)

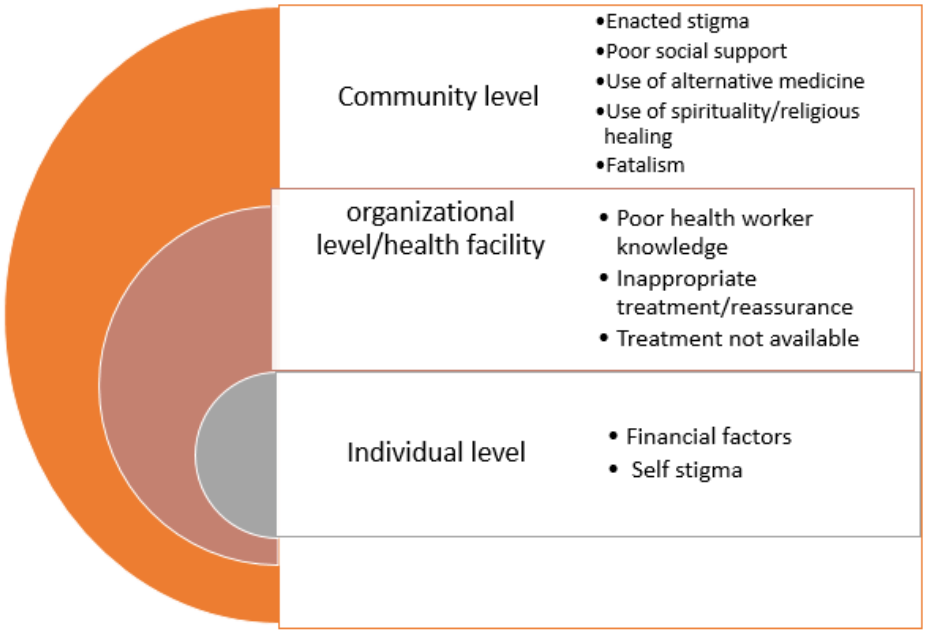
Stigma and other sociocultural factors

Sociocultural factors like stigma, myths around cancer and fatalism were prominent in these population and were a considerable cause of psychic distress in patients. The Dar survey revealed that, between 70- 82% of women subscribed to one or two myths about breast cancer (17). In looking closer at these sociocultural barriers, one begins to gain a deeper understanding of reasons why patients may present late with advanced disease.

Fear of stigmatization with subsequent family disruption or fragmentation may cause women to delay their health seeking behaviour. Our narratives show that this is a very legitimate concern in this setting with several women having their marriages disrupted, loss of livelihood and psychological distress, in the background of heightened distress

due to a cancer diagnosis. Similar findings were seen in Nigeria where a 3-year, post diagnosis review, of 88 breast cancer patients showed a divorce rate of 39 % in comparison to a national divorce rate of 2% (18). **Figure 1.2** provides a summary of the different barriers described in the study, within the context of the socio-ecological model approach.

FIGURE 1.2: SUMMARY OF BARRIERS IDENTIFIED USING A SOCIO_ECOLOGICAL FRAMEWORK



Barriers to treatment as identified in the study and applied to a socio-ecological model. Interventions at these different levels would be required.

To counter these barriers, we propose a multilevel approach that could help to improve the experience of breast cancer patients. In both countries studied, a national hospital insurance fund exists that caters to patient's financial needs. The national hospital insurance fund in Kenya has only been expanded to cover the cost of cancer treatment in the last three years. The impact of this has resulted in more patients receiving care but the long-term effects of this are largely unknown. However, in both systems, even when financial care is available, lack of equipment, medication stock outs still lead to delays in care. Even more far reaching may be the lack of awareness and inappropriate counsel provided by health workers which would serve to delay timely diagnosis and treatment. Interventions at the individual level and organizational level are required.

Individual interventions might involve patient education, microfinance initiatives to complement government funding and strengthening the role of family and support groups. Health worker education, especially targeting primary healthcare nurses, may be useful in strengthening referrals. Decentralizing care through developing regional centres of excellence, will decrease travel and waiting times at key facilities. Development of clear, well understood, bidirectional referral pathways will ensure that these centres are not congested and appropriate care given at each level. Investment in electronic health records and centralized stores will help to monitor medication flows and to prevent stock outs.

Community awareness can be increased through media campaigns, using opinion leaders at local levels like clan elders to spread the message. Uprooting the pervasive element of fatalism can only occur through shifting narratives and

encouraging survivors to share testimonials that work at removing both the stigma of cancer by discussing it openly and in enhancing perceptions that cure is possible. Education of traditional and spiritual healers and leveraging them into referral pathways could also help minimize delays.

Limitations

While qualitative data in this study are representative of both private and public health systems, it was not possible to interview patients from the public health system in Kenya. This is because for the period of the study, the public health systems were on strike. As health ecosystems differ, the results of our findings may not be generalizable to different countries. The authors maintain that there may be common themes in regions and these may be similar to findings in the Eastern Africa regions. Though regions may differ due to cross-cultural differences, many of the socio-cultural themes are applicable across many low and middle-income countries.

Conclusions

This manuscript serves to inform on the barriers and facilitators to care for women in East Africa with breast cancer. More needs to be done to improve health worker awareness and poor system referrals that result in delayed management of patients. The factors that were most disruptive were the socio-cultural factors such as stigma, which resulted in family disintegration. In patients who had good social support, even in the absence of personal financial resources, patients were able to complete their care. As efforts like the national hospital insurance funds are increasingly

strengthened in different countries in the region, it is important to consider nationwide interventions aimed at reducing stigma and ensuring successful reintegration of breast cancer survivors into their communities.

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CHAPTER TWO

THE ROLE OF STIGMA IN DELAYS IN THE MANAGEMENT OF BREAST CANCER IN LOW AND MIDDLE-INCOME COUNTRIES: A SYSTEMATIC REVIEW

Abstract:

In low and middle income countries, the majority of the women with breast cancer present with advanced cancers (stage 3 and 4 cancers). A combination of patient related and system related barriers result in delays in the diagnosis, treatment and follow up of breast cancers. Socio-cultural factors like stigma may play a role in patient delays. The aim of the study to determine the role of stigma as a barrier to care for women with cancer in low and middle income countries, and to determine what interventions have been tried to mitigate stigma in this setting and to determine the effectiveness of these strategies

Methods:

A search strategy was developed with a medical librarian. The librarian then performed a comprehensive search of several databases. These included OVID Medline, OVID Embase, CINAHL, Cochrane, and PsycINFO. Subject headings and key words were adapted for the other databases. No restrictions on language, the publication date, or type of article were placed

Results.

2372 articles were identified, 202 full text reviews performed and data extraction done on 38 studies from Africa and Asia. Anticipated stigma (21/38 studies,55.3%, CI, 38.3 -71.4%) and perceived stigma (21/38 studies,55.3%, CI 38.3 -71.4%) were the highest reported. Thirty five out of thirty-eight studies, (92.1%, CI 78.6-93%), mentioned other socio-cultural factors. The sociocultural factors mentioned in decreasing frequency were a) fatalism (65%), b) myths around breast cancer (47.4%), c) fear of surgery

(39.5%) d) conservatism (34.2%), e) use of alternative medicine (28.9%) f) spirituality/religion as a barrier (23.7%) and g) collectivism. Studies that had perceived stigma had higher rates of alternative medicine use (48%, 10/21) than studies that did not have perceived stigma (6%, 1/17). No other significant differences were found between studies that had perceived stigma and those that did not (p=0.21->0.95). No other significant associations were found between stigma, sociocultural factors, region or groups studied.

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Conclusion

Stigma in breast cancer continues to be prevalent in different populations across low and middle incomes globally. Urgent interventions are required as part of a multi-level plan to curb advanced disease at diagnosis of breast cancer and treatment discontinuations seen. These interventions will require an in depth understanding of the socio-cultural factors at play in that particular environment.

Introduction:

Over half a million women die annually of breast cancer, two thirds of whom live in low and middle-income countries (1). In these countries, the majority of the women with breast cancer present with advanced cancers (stage 3 and 4 cancers). (2) Early diagnosis and treatment is critical to reduce the morbidity and mortality of breast cancer. A combination of patient related and system related barriers result in delays in the diagnosis, treatment and follow up of breast cancers. (3). In low resource settings, patients are diagnosed late, and many do not complete their treatment. Socio-cultural factors like stigma may play a role in patient delays (4)

Understanding why patients are diagnosed late with breast cancer in low resource settings requires a multilevel approach. Delays are caused by factors which can be broadly divided into patient mediated and system mediated factors. (3,5) Patient related barriers include stigma and other socio-cultural factors and the lack of financial means. Patient mediated factors include socioeconomic factors like the level of education or employment status of women (6). This may influence the knowledge women have about the risks of breast cancer and their ability to access care. They also include socio-cultural factors like stigma, fatalism where there is the belief that death is inevitable, or collectivism where decisions are made as a community. Myths around cancer, use of alternative medication, and conservatism and modesty are other socio-cultural factors that may influence women's health seeking behaviour.

Though not as well explored, sociocultural factors like stigma may play a significant role in why patients are diagnosed late and why they do not complete

treatment. The term ‘stigma’ has its roots in the Greek terminology describing the branding/tattooing that would be done to distinguish deviant individuals in the community. Interaction with these individuals was to be avoided. (7) From early times, the notion of stigma has been associated with the labelling and isolating of individuals within a community. Erving Goffman in 1963 described stigma as a process through which an individual was perceived in a negative light by others either due to physical attributes, perceived character flaws or due to ethnicity. (8)

The HIV epidemic led to an academic focus on stigma and in interventions to reduce it. Applying this work to cancer patients, stigma can encompass negative social attitudes (perceived stigma) or discriminatory behaviours (enacted stigma) where patients are avoided. (9) Internalized stigma or self-stigma where patients are afraid of enacted stigma, whether or not it has actually occurred (anticipated stigma), has also been described. As a result of this fear, patients isolate themselves or try to hide their diagnosis. (9) Stigma could also extend to the patient’s immediate family or people who have had contact with the patient (secondary stigma) (see. table 2.1)

TABLE 2.1 TYPES OF STIGMA

TYPE:	
1.Experienced (enacted)	Stigma that occurs directly through interpersonal acts of discrimination
2.Perceived	Perception of the prevalence of stigmatizing attitudes in the community or among other groups e.g. healthcare providers
3.Anticipated	Fear of stigma whether or not it is actually experienced
4.Secondary	Stigma by association, extended to family or other caregivers of stigmatized individuals
5. Observed	Stigma occurring to others that is witnessed or heard about
6. Layered	Stigma experienced within different groups of overlapping populations that are marginalized/stigmatized

Adapted from Nyblade et al (9)

The socio-cultural lens also colours the way through which a particular society views woman with breast cancer. In a number of societies in low and middle incomes, there is a high social stigma associated with breast cancers. A diagnosis of cancer has significant implications on women and their families. This systematic review aims to determine the role of stigma as a barrier to care for women with cancer in low and

middle income countries, and to determine what interventions have been tried to mitigate stigma in this setting and to determine the effectiveness of these strategies.

Materials and Methods

Search Strategy

A search strategy was developed with a medical librarian. The librarian then performed a comprehensive search of several databases. These included OVID Medline, OVID Embase, CINAHL, Cochrane, and PsycINFO. Subject headings and key words were adapted for the other databases. No restrictions on language, the publication date, or type of article were placed. Additional articles were incorporated by reviewing reference lists and forward citations of selected articles. The full search strategy is described below (see appendix 2).

Inclusion and Exclusion Criteria

Studies that mentioned a barrier, delay or interval in the time of treatment were identified. The primary outcome of interest was any study that listed stigma as a barrier to care or a delay in the presentation or treatment of patients. A secondary outcome was any study that listed interventions to mitigate stigma. These studies had to be performed in either low and middle income countries as defined by the World Bank Criteria. Classification of the income status of the country was as per 2018 World Bank Criteria (10). All publications were included to reflect the breadth of publications around this subject.

We included peer review articles that had been approved by an IRB and excluded abstracts, commentaries and other reviews. Studies that addressed stigma in patients in a low or middle income setting or any studies addressing community perceptions of stigma or interventions as relates to breast cancer patients were included.

Figure 2.1 shows the PRISMA flow diagram that summaries the approach to study selection. (figure 2.1) Any molecular, genetic or any animal studies on breast cancer were excluded. After review of 202 full texts, 38 studies were selected for data extraction.

FIGURE 2.1: PRISMA - Preferred Reporting Items for Systematic reviews and Metanalyses flow chart

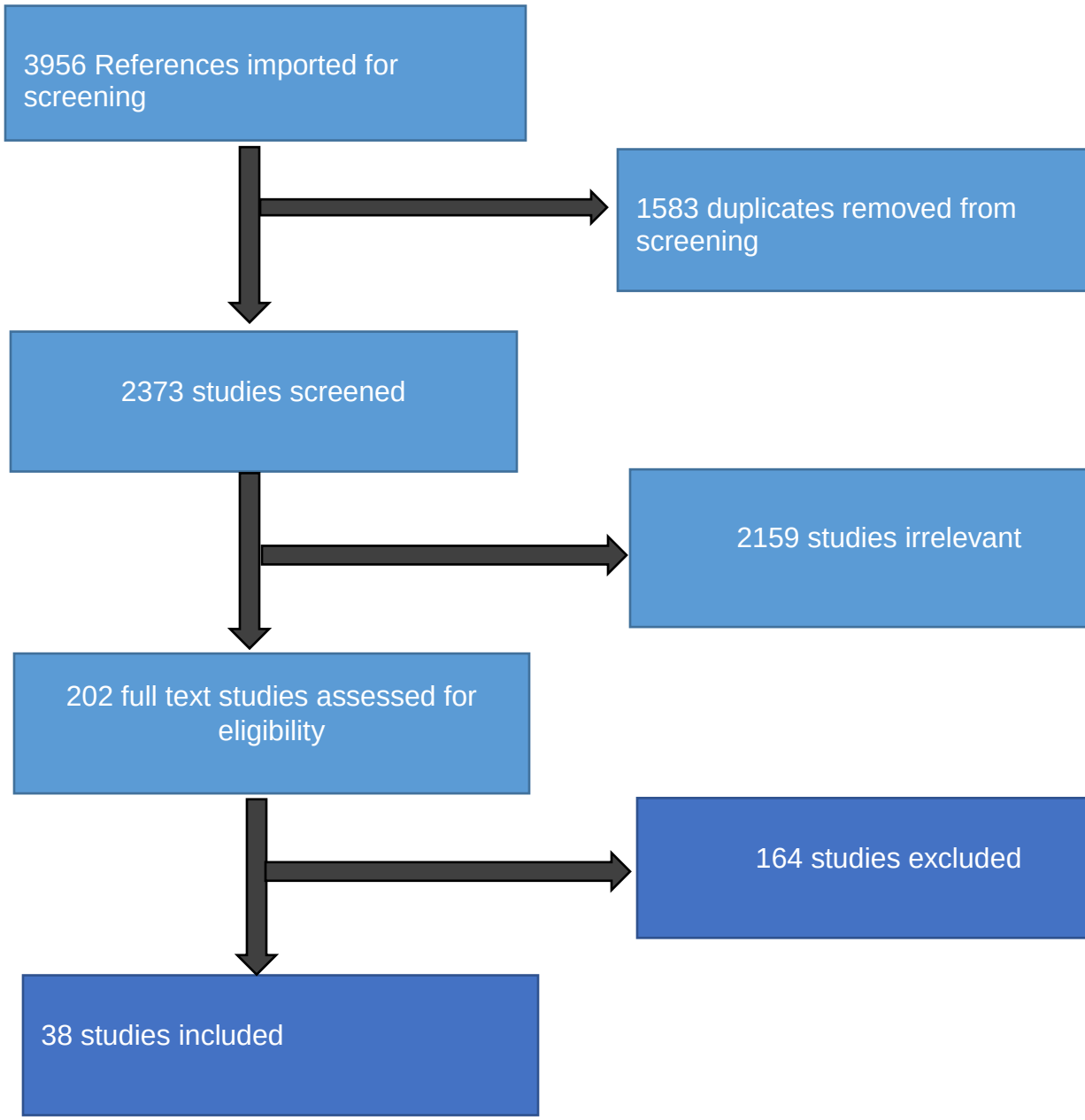

Figure 2.1: PRISMA flow chart

Data Process

Studies that were identified through a database search were uploaded onto a Web-based systematic review software package Covidence (https://www.covidence.org/). Initially, abstract and title reviews of all studies were completed independently by 2 teams of 3-4 authors. Each study had to be reviewed independently by at least two authors. Any differences of opinion were discussed and resolved by discussion with the two authors or by involving a third author when no consensus could be reached. Full text screening was done by the same team and each paper had to be reviewed independently by at least two authors. Results were then compared across different teams. Any discrepancies were resolved after discussion or by incorporating a third author. In the full text review, a comprehensive log was maintained for studies that were excluded and the reasons behind exclusion were noted. (see table 2.2)

TABLE 2.2: Reasons for exclusion from systematic review.

164 studies excluded	
67studies -wrong outcomes	Studies addressed other barriers to care but no stigma
40 studies - wrong design	Case reports, abstracts, letters to editor
24 studies- passing reference to stigma	Mention of stigma in discussion or introduction but not in study results
17 studies- No mention of stigma	Studies do not address any barriers to care or stigma

9 studies wrong patient population	Studies involving other cancers but no breast cancer mentioned or involving immigrant populations
5 studies duplicated	Studies appear twice in review
2 studies -wrong setting	Studies done in high income countries

Data Extraction

A comprehensive data extraction form was designed and tested. The data extraction form included the different types of stigma adapted from Nyblade and colleagues (9), other sociocultural factors that were mentioned alongside stigma, any interventions or any recommendations made to reduce stigma. Data extraction was performed by 2 teams of authors comprised of 3-4 authors who reviewed their work internally, then reviewed the studies extracted by the opposite team. Features of the study including the preliminary data (authors, year of publication, journal, country of study etc, were recorded. Specific data points were then recorded using the data extraction form and template. (see appendix 3). For qualitative studies emergent themes were identified and recorded.

Assessment of Quality

A detailed analysis of the quality of the studies included in the review was performed. Quantitative studies were evaluated using the assessment tool QUALSYST which provides quality criteria for studies using quantitative and qualitative methodology (11). Studies using quantitative methodology were assessed on 12 items including study design, method of subject selection, response rate, sample size, analytic

methods, and whether conclusions were supported by the results (see addendum). This tool rates each of these as yes (2) partial (1) or no (0) or not applicable with a maximum score of 24 points.(appendix 4)

For qualitative studies, we used the Consolidated Criteria for Reporting Qualitative Studies (COREQ), a checklist that consists of 32 criteria, which is a tool developed to streamline the reporting of qualitative studies. The checklist is divided in three domains that reflect on i) the characteristics of a research team and ii) features of study design including patient selection and recruitment and iii) analyses and findings from the study (12). (appendix 5)

Data Synthesis

Following data extraction and quality assessment a meta-synthesis was considered but due to the heterogeneous nature of the data, qualitative and quantitative studies were analyzed independently.

Data analysis

Study characteristics and overall sample characteristics were described. Stigma rates and sociocultural factor rates were described with binomial proportions and exact 95% confidence intervals (CI). Differences in stigma rates and sociocultural factors by sample and study characteristics were assessed with Fisher's Exact test. As this analysis was preliminary and solely exploratory, no hypothesis test corrections were performed. Two-sided p-values less than 0.05 were considered statistically significant. All analyses were performed with SAS 9.4 (The SAS Institute, Cary, NC).

RESULTS

Thirty-eight studies were selected for inclusion. These included 29 qualitative studies, 7 quantitative studies and 2 mixed method studies. (appendix 6)

Study Characteristics

The majority of studies were from Asia (26 studies, 68.4%) and the remainder from Africa (12 studies, 31.6%). Most studies were from the Middle East and South Asia regions (60%). Most of the publications (33 out of 38, 86.8%), were after 2010, and published mainly by journals in the United States (34%) or by journals in the United Kingdom (39.5%). The study setting was listed in most papers and was mainly urban. (Table 2.3).

TABLE 2.3: Study characteristics

# Studies		38 (%)
Year of Publication	pre-2010	5 (13.2)
	2010-2014	23 (60.5)
	2014-2018	10 (26.3)
Country of Publication	United Kingdom	15 (39.5)
	United States	13 (34.2)
	Other	10 (26.3)
Study Continent	Asia	26 (68.4)
	Africa	12 (31.6)
Study Region	Middle East/South Asia	23 (60.5)
	East Asia	4 (10.5)
	South Africa	4 (10.5)
	West Africa	4 (10.5)
	East Africa	3 (7.9)
Study Setting Available	Yes	29 (76.3)
Rural Setting	Yes	11 (28.9)
	Unknown	7 (18.4)
Semi-urban Setting	Yes	2 (5.3)
	Unknown	8 (21.1)
Urban Setting	Yes	26 (68.4)
	Unknown	8 (21.1)
Quantitative Study Methods	Yes	8 (21.1)
Qualitative Study Methods	Yes	32 (84.2)
Design Methods:		
Cross-Sectional Design	Yes	7 (18.4)
Focus Groups	Yes	10 (26.3)
Self-Administered Questionnaire	Yes	3 (7.9)
Validated Questionnaire	Yes	2 (5.3)
	Unknown	1 (2.6)
Semi-Structured Interview	Yes	19 (50)
Structured Interview	Yes	6 (15.8)

Table 3: Study characteristics. *Other countries of publication include Thailand, India, Iran, Netherlands, and South Africa. Study settings are not mutually exclusive*

Study Population

The studies had different samples with 25 studies (66%) involving breast cancer patients and another 17 involving either health care professionals (nurses or doctors), or women or men in the community or patient caregivers. (Table 2.4).

Twenty-five studies (66%) included breast cancer patients and of these, 15 had stage data available (58%). The median sample size was 20 patients (range: 5-175). Of the studies involving breast cancer patients, 15 out of 15 studies dealt with patients with advanced disease (stage 3 and 4). Eight studies also dealt with patients with early cancers (stage 1 and 2). Non-breast cancer individuals were included in 17 of the 38 studies (45%). Most commonly, women of the community were included (13/38, 34%)

Table 2.4: Study Sample Characteristics

		N (%)
Included:		
Breast Cancer Patients	Yes	25 (65.8)
Available Stage	Yes	15 (57.7)
Stage 3 Patients	Yes	9 (23.7)
	Unknown	11 (28.9)
Stage 4 Patients	Yes	6 (15.8)
	Unknown	11 (28.9)
Early Stage Patients	Yes	8 (21.1)
	Unknown	11 (28.9)
Late Stage Patients	Yes	12 (31.6)
	Unknown	9 (23.7)
Completed Treatment Patients	Yes	8 (21.1)
Breast Cancer Survivors	Yes	1 (2.6)
Total # Breast Cancer Patients	Median (range) (N=26)	20 (5-175)
Non-Breast Cancer Participants	Yes	17 (44.7)
Caregivers	Yes	1 (2.6)
Doctors	Yes	1 (2.6)
Nurses	Yes	2 (5.3)
Spouses	Yes	1 (2.6)
Men from Community	Yes	2 (5.3)
Women from Community	Yes	13 (34.2)
Total # Non-Breast Cancer Participants	Median (range) (N=17)	45 (4-300)

Documented treatments received by the breast cancer patients in the studies were surgery, chemotherapy and radiation treatment. (Table 2.5).

Table 2. 5. Treatment Characteristics

		N (%)
Patients Received:		
Chemotherapy	Yes	13 (34.2)
	No	2 (5.3)
	Unknown	23 (60.5)
Radiation	Yes	8 (21.1)
	No	7 (18.4)
	Unknown	23 (60.5)
Surgery	Yes	14 (36.8)
	No	3 (7.9)
	Unknown	21 (55.3)
Treatment Delays Experienced	Yes	13 (34.2)
	No	25 (65.8)
Country has Nationalized Healthcare	Yes	4 (10.5)
	No	34 (89.5)
Country has Universal Screening	Yes	6 (15.8)
	No	32 (84.2)

Of studies reviewed, 13 out of 38 studies listed treatment delays (38%), in the management of breast cancer patients. Only 4 out of the 38 studies reviewed, listed a nationalized health care/insurance plan in the countries of study (10.5%) and only 6 studies mentioned available access to universal screening for breast cancer (15.8%).

Types of Stigma

The different types of stigma were recorded and examples of these different stigma types extracted from the text (Tables 2.6,2.7). Of the manuscripts reviewed, 37 out of 38 directly reported stigma (97.4%, CI 86.2-99.9%). One paper did not mention stigma directly but gave several examples of the different stigma types. Anticipated stigma (21/38 studies,55.3%, CI, 38.3 -71.4%) and perceived stigma (21/38 studies,55.3%, CI 38.3 - 71.4%) were the highest reported. Layered stigma was the lowest reported (3/38 studies, 7.9%, CI 1.7%-21.4%). Supportive quotes and statements from the literature were obtained. (Table 2.7, 13-18)

TABLES 2.6, 2.7: STIGMA TYPES AND QUOTES:

Stigma Type	Fraction	Proportion	[95% CI]
Reported	37/38	97.4%	[86.2% - 99.9%]
Anticipated	21/38	55.3%	[38.3% - 71.4%]
Experienced	11/38	28.9%	[15.4% - 45.9%]
Layered	3/38	7.9%	[1.7% - 21.4%]
Observed	4/38	10.5%	[2.9% - 24.8%]
Perceived	21/38	55.3%	[38.3% - 71.4%]
Secondary	8/38	21.1%	[9.6% - 37.3%]

TABLE 2.7: STIGMA QUOTES

STIGMA TYPES	QUOTES
Enacted/Experienced	*"Family members feel that they will get the disease if they meet me. That is why I am alone."13* *"When I got the disease, he told me, 'You deserve it because you have extreme hate inside. God is punishing you'. He beat me, he hit me with a chair, he suffocated me, and threw me out of the home."14*
Anticipated	*….I have been crying since the diagnosis… I want to marry…breast cancer means that you are finished. I don't think any man may accept marrying a woman with breast cancer.'14*
Perceived	*I cannot participate in social events. Because everyone in the environment considers cancer as something bad and they look at me differently15*
Observed	"*I know a young woman who had breast cancer; her husband married her best friend, Poor woman, her children are still young and can't take care of her" 16* *"I know a woman who had breast cancer her husband rejected her and married another woman because she lost her femininity" 16* *"I have seen when my relative suffered from BC, blood used to come from her breast. At that time their landlord asked them to leave their house as it can affect his children. Even her husband used to scold her and was not supportive. He was saying her it is better if you die." 17*
Secondary	*"I am worried about my children. I came here with my husband and left my children alone as the village people don't care about my children in case they get the same disease."13*
Layered	*...I not only have breast cancer, but advanced breast cancer, I have HIV, I have no child, I have fibroids and my husband is dead...I had given up on life and thought I only deserved to die..so my experience has been a terrible one something I could not run away from, 18*

Sociocultural factors:

Stigma was rarely reported in isolation and was associated with other sociocultural factors. These frequently had a summative effect in increasing patient delays. Thirty five out of thirty-eight studies, (92.1%, CI 78.6-93%), mentioned other socio-cultural factors. The sociocultural factors mentioned in decreasing frequency were a) fatalism (65%), b) myths around breast cancer (47.4%), c) fear of surgery (39.5%) d) conservatism (34.2%), e) use of alternative medicine (28.9%) f) spirituality/religion as a barrier (23.7%) and g) collectivism. Supportive quotes and statements from the literature were obtained (Tables 2.8 and 2.9, 19-24)

TABLES 2.8,2.9: Socio-cultural factors and quotes

Sociocultural factors	**Fraction**	**Proportion**	**[95% CI]**
Any sociocultural factors reported?	35/38	92.1%	[78.6%- 98.3%]
Fatalism	24/38	65.8%	[48.6%- 80.4%]
Myths	18/38	47.4%	[31.0%- 64.2%]
Fear of Surgery	15/38	39.5%	[24.0%- 56.5%]
Conservatism	13/38	34.2%	[19.6 % - 51.4%]
Alternative Medicine	11/38	28.9%	[15.4%- 45.9%]
Religion/spirituality as barrier	9/38	23.7%	[11.4%- 40.2%]
Collectivism	2/38	5.3%	[0.6%- 17.7%]

TABLE 2.9: SOCIOCULTURAL QUOTES

Socio-cultural factors	
Fatalism	*I was hopeful about life and now I don't know about life because this disease is terrifying and everyone says that this disease is related to death. All my cousins came and started crying for me. I don't even want to buy things because I am going to die. I have left everything..13*
Myths around cancer	*'Cancer is contagious' 13* *'Cancers are due to promiscuity'19* *Some think it is contagious and if a man's wife is inflicted with breast cancer, this would bring shame to him and his family34*
Conservatism	*. . I cannot allow another man to touch my breast . . . I would be accused of being adulterous if found in such a compromising position . . . I do not want to be divorced, which will bring disgrace upon my family . .20*
Fear of Mastectomy	*I have sacrificed my hair, I was ready to do that I am just praying that the sacrifice ends here and I won't have to go on and have a mastectomy done. If the cancer was at stage four I will refuse treatment.21*
Collectivism	*'I suspected it was breast cancer when I found the lump, I told my husband. He refused to believe. He was in denial. I did not want to upset him. I listened to him. 22* Most participants (n=50)* consulted a traditional healer after they had received a breast cancer diagnosis in a district hospital. Several reasons accounted for their decision to consult a traditional healer, namely: recommendation from their husband or relatives 23
Alternative medicine	*'Due to a lack of knowledge, when they hear the word cancer they get scared, some hide it and some use traditional medicine until it becomes too late for treatment'23* *"I was really afraid of surgery, it was not wrong to try another treatment such as herbal medicine and another method of traditional treatment which were more comfortable for me"24*
Religion/Spirituality as a barrier to treatment	'*I didn't visit the local healer but always drink holy water and also apply emnet (holy mud) on my breast'. 23*

Stigma reduction:

A number of papers proposed strategies to counter stigma. These included education of women and cancer advocacy (25), involvement of spiritual healers/ traditional healers in health promotion (20), and education of spouses (20). They also included using forums where women traditionally gather such as places of worship and women's meetings.

Associations: (supplementary material a)

a) Continent versus stigma/sociocultural factors

A comparison of stigma and sociocultural factor rates between the two continents was performed. No significant differences in stigma rates were noted between Asian countries and African countries (p=0.23->0.95). However, studies from Africa reported higher rates of alternative medicine use (58%, 7/12) compared to studies from Asia (15%, 4/26), p=0.017. Additionally, studies from Africa reported higher rates of myths (75%, 9/12) compared to Asian studies (35%, 9/26), p=0.035. No other significant differences were noted in sociocultural factors (p=0.16->0.95) (supplement a).

b) Region of study versus stigma/sociocultural factors

A further comparison of stigma and sociocultural factor proportions by region was performed (supplement a). Similar to the continent breakdown, no significant differences in stigma were noted (p=0.33->0.95), and alternative medicine rates were higher in other countries (60%, 9/15) compared to the Middle Eastern countries and India (9%, 2/23), p=0.001. Additionally, fear of surgery was marginally higher in other countries

(60%, 9/15) compared to Middle Eastern countries and India (26%, 6/23), p=0.049. No significant differences in myth rates (p=0.32) or other sociocultural factors were found (p=0.27->0.95).

c) Rural settings and stigma and sociocultural factors

A comparison of stigma and sociocultural factor rates between the rural study settings was done. No significant differences in stigma rates were observed between studies that included rural participants and those that did not (p=0.27->0.95). Similarly, no significant differences were found in the rates of sociocultural factors (p=0.13-0.68)

d) Breast cancer patients and stigma type and sociocultural factors

A comparison of stigma and sociocultural factor rates between studies that included breast cancer patients and those that did not was performed to see whether they were any unique trends between these two different populations. No significant differences in stigma rates were noted between these studies, although experienced stigma approached significance (p=0.060, others p=0.31->0.95). Studies that included breast cancer patients had higher rates of experienced stigma (40%, 10/25) compared to studies that did not include any breast cancer patients (8%, 1/13). Studies that did not include breast cancer patients reported higher rates of religious sociocultural factor (46%, 6/13) compared to studies that included breast cancer patients (12%, 3/25), p=0.040. No other significant differences in sociocultural factors were found (p=0.31->0.95). (supplement a)

e) Publication year and stigma, sociocultural factors.

Comparison of stigma and sociocultural factor rates by publication year was performed to see if there was any increase in reports of different types of stigma. No significant differences were found in stigma rates (p=0.26-0.80) or sociocultural factors (p=0.10->0.95). (supplement a)

f) Stigma type and sociocultural factors

Comparison between different stigma types and sociocultural factors was done to see whether one could predict any clustering of sociocultural factors with a particular stigma type. Studies that had perceived stigma had higher rates of alternative medicine use (48%, 10/21) than studies that did not have perceived stigma (6%, 1/17). No other significant differences were found between studies that had perceived stigma and those that did not (p=0.21->0.95). No significant differences were found between studies that had anticipated stigma and those that did not (p=0.15->0.95), and studies that had experienced stigma and those that did not (p=0.24->0.95). This was also true for studies that had layered stigma and those that did not (p=0.20->0.95) and for studies that had secondary stigma and those that did not (p=0.22->0.95). (supplement a)

DISCUSSION:

Breast Cancer: Perceptions of self and Society forming barriers to care

The breast is intrinsically tied in with both women's and society's perceptions, of the role of women and with sexuality and an individual's perception of self. Breast surgery for instance, is one of the surgeries associated with a very high psychological

impact, as it affects women's perception of their body image. (26) The treatment received for breast cancer (surgery, chemotherapy) may affect a woman's individual perceptions of self, their sexuality and their child bearing capacity.

In addition, the broader community in which a patient exists, has implications on how an individual perceives herself and her worth in that society. Depending on the social support that exists and society's perceptions, this could potentially act as a barrier to access to care. In many communities in sub-Saharan Africa for instance, the role of women has been traditionally defined as that of child bearing and rearing (4). The role of the female has been defined as a care provider and a pillar of family support. Any illness that compromises her ability to fulfil her family duties, may be perceived negatively by the community and may act as a threat to her family stability. (4)

In Nigeria, a recent study showed that married women undergo a significant number of challenges following the diagnosis of breast cancer. In a review of 81 patients, almost a third of women were divorced or separated (38.3%) at three years' post therapy, compared to a national average of 2.6% in Nigeria. (27). In south East Asia women are concerned that their husband will divorce them once they have a breast cancer and thus delay seeking treatment for breast lumps (17). This same fear was echoed among women in Uganda (East Africa) (28).

"*So if they start thinking of cutting off the breast and what, they get scared.... mostly because they fear losing their families, their husbands. I look at it as that is the biggest problem. They shy back, stay with their lump until the lump grows until it can't be contained anymore. That is why they report late and it gets so obvious and they can't keep it anymore."* (28*)*

In other societies, it is taboo to talk about concerns involving reproductive system organs and this can delay health seeking behaviour of women (17). Some communities have no word for breast cancer and breast concerns are interpreted in the light of prevalent myths and misconceptions around cancer (23).

Stigma in care

Our results showed that stigma was prevalent in both Asian and African populations whether in the perception of people in the community or among health workers. Stigma amongst health workers was present with health workers blaming patients for getting the disease (25) and one study noting a higher perception of stigma among health workers than in the community they served, in Pakistan (29). Though there may be a number of reasons to explain this finding, inherent health worker biases could potentially impede patient care. These findings are in keeping with other studies in HIV where health workers would occasionally act as barriers to care (30,31,).

It was also interesting to note that though breast cancer patients were themselves stigmatized, they also stigmatized other cancer patients in certain situations. In a qualitative study involving both breast and cervical cancer patients, cervical cancer patients remarked that breast cancer patients did not want to associate with them as they felt that they (breast cancer patients) had a more ‘socially acceptable’ cause of illness than cervical cancer patients who were perceived to be promiscuous.(25) This might be less of individual perspectives among breast cancer patients, but more reflective of a broader sense of how different patients are viewed in that particular community.

Self Stigma: Perceptions of self

Stigma remains high in breast cancer patients who feel that they are the cause of shame and abuse in the community. Breast cancer patients internalize perceptions of the community and inadvertently perpetrate stigma by avoiding situations and places or by withdrawing from social interaction.

'I have a bad disease, and it is disgusting. My breast was cut out… it left only ugly scars on my chest. It looks very ugly, you see… it is a shame for women' 24

Social isolation remains high with patients feeling frequently misunderstood and unable to express or talk about their feelings to anyone.

'I felt that sharing stuff with others might bring disease to them. I felt it can contaminate my kids. Even though mor (doctor) confirmed it is not a communicable disease, it reminded me that I am a sick person'. 24

No one wants to talk about it, it seems as if it's forbidden to talk about and raise' 23

Though these arbitrary divisions of the different types of stigma exist, the reality is a much more complex picture and interaction of several elements of stigma. Despite the different classifications of stigma, this is in essence a continuum with various levels of interphase. The reality is that one could experience, view or interpret stigma in a number of ways. For instance, a breast cancer patient worried about not having her daughters married could point perhaps to both the perceptions of breast cancer in that society(perceived), stigma by association (secondary) and indeed a fear of stigma that has not yet happened. (Anticipated)

Sociocultural factors as barriers to care

A number of upstream determinants of health including gender equity play a key role in understanding the health seeking behaviour of women in many developing countries. The millennium development goals and subsequent sustainable development goals are aimed at providing equity and empowering women in societies, as an initiative to improve access to care for women globally (32).

In sub -Saharan Africa for instance, women will wait an average of 11 months before presenting with a breast lump (4). Literacy levels had no bearing on attitude and knowledge around breast cancer, implying there must be other drivers for these delays (4). These drivers may be largely socio-cultural. A qualitative study amongst women who were mostly university graduates in Uganda, revealed views that women would rather not engage or complete their care, than have people know their diagnosis, in order to avoid social exclusion (28). Our findings are in keeping with reports from literature as we noted no significant findings existed between stigma and rural or urban populations, between patients or people in the community or in different regions of study, suggesting that stigma is a pervasive entity that permeates all sectors and strata of a particular community.

In many developing countries women are not the primary determinants of their health seeking behaviour. In sub-Saharan Africa for instance, though women form over 75 % of the workforce, more than 60 % are involved in subsistence farming and do not have a consistent income (33). They may have to rely on a partner or family for money to access care. (4) In addition, in many social constructs, women have to get permission from their spouse or family member in order to access or receive treatment (17).

Women in Kenya listed spousal lack of support as a potential barrier to accessing care (34). Similar findings are noted in south East Asia and Arabic nations.

The approach to health in many cultures in low and middle income settings may vary. There is frequently an aspect of 'collectivism' where an approach to treatment is not determined by the individual primarily but is decided on by the greater community. In addition, the decision to receive treatment was made by the community (23). Women from South East Asia and Ethiopia report that they were frequently asked to start complementary alternative medicine by their families/clan or by recommendation from a spouse (21). It is taboo in certain cultures for a woman to disobey the treatment directives given by the clan/community. This is further exacerbated by a paternalistic approach to medicine with patients citing that no adequate explanations to their treatment was provided by clinicians before initiation of care. (24) This leads women to feel out of control, of their own health decisions and as such diminishes their agency as illustrated below.

"I am a low educated person and come from a rural area; I just follow the doctor's advice for my health and I do not dare to ask anything" 24

In other instances, modesty and conservatism play a role in facilitating delays. Reports from Abruidis in Sudan showed that women would not seek care due to shyness or embarrassment over being examined by a male physician (35). There may frequently be an interplay of religion and culture and reports from West Africa and the

middle east show that some women believe, that it may be against their religion or culture, to have a male examine them (20). It may be also regarded as taboo to expose certain areas of the body which should be covered up (20) .This construct could be further reinforced by culture. For instance, in a recent study of 50 men in the middle east, only 8 men would allow their wives to be examined by a male doctor, and only if it was a matter of life and death and not routine screening. (36). They would however be willing and eager to encourage their wives to participate in a breast screening program, if a female doctor was available. This underscores the need for culturally appropriate interventions.

In many cultures, there is a pervasive element of fatalism around cancer.(13, 23) People believe that cancer is predestined and may be one's fate. Since this is already predetermined, one should accept this and die. Self-fulfilling myths may be sustained in communities where patients believe that one 'goes to the hospital to die'. This is frequently the case, when patients present with advanced disease and try conventional medicine as a last ditch resort having exhausted alternative sources of treatment

Recommendations for stigma reduction

a) Education of women

Studies suggested that education of women was key. This could involve using cancer advocates or community role models. They could be encouraged to get involved in breast cancer awareness and educational campaigns aimed at reducing social stigma. Suggestions included using breast cancer survivors in campaigns to change the narrative around breast cancer from certain death to survival (25).

Community events such as meetings and other gatherings were identified as appropriate places for promoting health education, as the majority of community members attend these gatherings. Additionally, it was suggested that health personnel organize special education programs for women. (21) Studies suggested that women's groups in the district can also be utilized as a cancer aware-ness campaign tool. The formation of women social groups is a key feature in small communities and these could be targeted.

b) Involvement of spiritual healers/traditional healers.

Many patients attach a spiritual etiology to their cancer. As a result, a number of individuals will seek out traditional or spiritual healers to address or treat the cancer. Patients suggested including these healers (20) in the care management plans or educating them so as to enhance patient engagement and retention in conventional medical treatment.

c) Education of spouse/partners

Education of partners was suggested in a number of studies as a way of reducing stigma. Getting partners to accept their partners, post diagnosis was suggested as a way to address the perceived stigma around breast patients. As many populations attributed breast cancer to promiscuous or dubious behavior like being involved in witchcraft, it would be important to educate partners and the broader community to accept cancer patients. In addition, if women were less worried about losing their marriages and families, they are likely to present earlier.

However, it is important to note that different socio-cultural factors may come into play when suggesting different strategies. For instance, women stated they found listening to breast cancer survivor stories as not helpful and distressing, especially if survivors shared negative experience, as illustrated below.

"I knew one and we became friends, then she started to complain, I have back pain, so I started to have the same complaints, so I stopped sitting next to her"14

Limitations:

Due to small number of studies derived it is difficult to draw any broad conclusions. In addition, due the predominantly qualitative nature of the studies involved, it would be difficult to generalize this to multiple populations. However, we noted that regardless of the region, stigma around breast cancer was prevalent and though assigned different aetiologies or causes, the end result was ostracization of the individual with often resultant significant psychological distress. None of the studies reviewed discussed any interventions aimed specifically at reducing stigma highlighting a gap that requires urgent intervention.

Conclusion:

Stigma in breast cancer continues to be prevalent in different populations across low and middle incomes globally. Urgent interventions are required as part of a multi-level plan to curb advanced disease at diagnosis of breast cancer and treatment discontinuations seen. These interventions will require an in depth understanding of the socio-cultural factors at play in that particular environment.

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APPENDIX 1:

INTERVIEWERS/MODERATOR GUIDE –BREAST CANCER

Introductory questions. What year were you first diagnosed with breast cancer? How many years have you lived with breast cancer?

Transition question. Tell me about the treatment you received when you were diagnosed with breast cancer to date. How long did it take? Any delays?

Key questions:

1.**What helped you go through the treatment once you received your diagnosis?**

2.**What did you find challenging?Were you able to overcome these challenges?**

Probe-How were you able to do this? Could you give me some examples?

3. Looking back over your treatment/cancer journey, what emotions come to mind?Tell me a little more about this.

Probe: Why did that emotion come to mind? Do you have instances that you remember

4. Are there people in your life who help you when you are in need of something? How do these people help? **Are there people who make it difficult for you to obtain what you needed?** How did they do this?

Probes-Are you married/have a partner? What do they think about your breast cancer?

-What do your family/friends say about your breast cancer? (do they know your diagnosis?)

-Are you working? What do your co-workers/boss say?

5. Tell me about your relationship with the doctors/medical staff treating your breast cancer?

Probes: - What things could affect the treatment people receive from medical staff or doctors?

-What do you understand about seeing your doctor/oncologist. Is there a regular doctor you see?

-Are there any organisations or institutions that support you with this?

6. Are you on any medication for your cancer? What is the experience with this?

Probes-any new effects? Are you taking it regularly? Is it accessible/available always?

7. Some people say that people who get cancer may have done something to cause it? What would you tell them?

Comment: This is a question designed to interrogate/determine beliefs around breast cancer. An initial study showed a high prevalence of myths around breast cancer.

Closing

So you said (patients words) ……..makes it easier/difficult to get the healthcare you require?

Is there anything else you would like to share with me about your cancer experience?

What could be done to make it easier for you and other ladies to go through treatment and receive care now?

Thank you so much for your time and for sharing with us this important information.

Approach to the summary

This closes the loop of the discussion and helps to clarify the themes discussed. It is also an opportunity to explore any unmentioned areas and views that the patient has.

Appendix 2:

Systematic review search strategy

WEILL CORNELL SEARCH STRATEGY

Contents

Original Request

Qualtrics Submission for Systematic Review at 03/15/17 3:15 PM

Response Summary:

Name:

Miriam Mutebi

CWID:

mim2072@med.cornell.edu

Institution:

Weill Cornell Medical College

Department:

Medicine

Phone:

6466441726

Email:

Mim2072@med.cornell.edu

Status:

Fellow/Resident

Proposed title:

Women and cancer: understanding barriers and facilitators to the diagnosis, treatment and follow up of breast and gynecological cancers in low and middle income countries

Timeframe for completion for search:(Generally searches for published and unpublished studies average three to eight months)

11/01/2017

Intended systematic review submission date:

02/12/2018

Type of project:

Course research project

What is the aim of this systematic review?

To understand the barriers to the management of breast and gynecological cancers in developing countries where patients typically present with advanced disease and to explore strategies/interventions that exist that mitigate these barriers.

Please list the members of your systematic review team and their role (Name, Role, Email):

1.Miriam mutebi -PI - mim2072@med.cornell.edu / mcmutebi@yahoo.com

2. Dr Andrea Pusic - pusica@mskcc.org - mentor

3. Dr Peter Kingham- kinghamt@mskcc.org- mentor

4. Dr Asad Raja- asad.raja@aku.edu- mentor

5. Dr Marleen Temmerman- Marleen.temmerman@aku.edu -mentor

Patients, population or problem: (Important characteristics including disease/condition, age, gender, race/ethnicity)

Women with breast cancers in developing countries (Africa)

Intervention: (Drug/treatment; diagnostic test/screening test; exposure; prognostic factor/risk factors/lifestyle)

Management I.e. Diagnosis, treatment, follow up

Barriers to management

Facilitators to management

Outcome: (What to measure - improvement in health; prevention of illness; adverse events; accuracy)

Delay in diagnosis, delay in treatment,

Mortality, premature deaths

Please restate your question using components of PICO:

To determine stigma as a barrier to management of women with breast cancer in low and middle income countries

Relevant terms: (Please list significant words, phrases, and acronyms)

Breast neoplasms

Barriers to care

Access to care

Delays

Diagnosis

Treatment

Follow up

Stigma

LMICs

Sub Saharan Africa

Relevant databases: (Please list relevant resources that should be searched. Note that the librarian may also offer recommendations)

Pub Med

Medscape

Google scholar

African journals online

Gender:

Female

Age range (select all that apply):

Adult: 19-44 years

Middle Aged: 45-64 years

Middle Aged and Aged: 45+ years

Elderly: 65+ years

Languages:

English and foreign language articles with English abstracts

Publication years:

Current year + 10

Humans only studies:

Yes

What kind of study designs should be captured by the search? (select all that apply)

Randomized controlled trials

Controlled trials

Cohort studies

Case control studies

Case series

Which of the following publication types are appropriate? (select all that apply)

Research articles in journals

Comment, editorial, letter

Books/book chapters

Conference proceedings/meeting abstracts

Dissertations/theses

Research in progress

How many results do you expect to find on this topic?

100-200

How many citations are you willing to review?

800-1000

Have you already identified any relevant articles or authors? Please include citation or PMID: (Please also include the names of any resources you have already searched)

Systematic review of barriers to breast cancer care in developing countries resulting in delayed patient presentation Sharma K, CostasA, Shulman LN, Meara JG

PMID:22956949 pubmed

Should auto-alerts be generated? (Auto Alerts are a personalized current awareness service via email. Databases searches are run at selected time intervals, obtaining the most recent additions to the database that fit your search parameters)

Yes

How do you want the results delivered?

Excel

Additional comments:

An initial pub Med search revealed about 100 articles however there may be a need to have search engines that list more African studies like African Index Medicus etc. I limited the search to articles that are written in English or have a translation for ease of data extraction

In the interests of producing the most valid search strategy, may we ask for outside review?(In accordance with IOM standard 3.1.3 for Systematic Reviews, I agree to allow “an independent librarian or other information specialist to peer review the search strategy” developed by a WCMC Librarian)

Yes

Librarian Timeline and Feedback

LIBRARIAN ROLE IN THE SYSTEMATIC REVIEW (SR) COLLABORATION INCLUDES

- Translating the research question into an appropriate search strategy for each database.
- Translating the concepts into controlled vocabulary and keywords so that retrieval is maximized at the same time as being precise.
- Recommending pre-existing filters.
- Recommending specific databases and other information sources to be searched.
- Conducting the literature searches.
- Delivering the results using a bibliographic management tool.
- Running search updates in selected databases (as needed).
- Recommending journals for publication based upon manuscript subject area, impact factors and journal submission guidelines.
- Once the SR is completed, the librarian writes the literature search methodology section for the submitted manuscript, maintains records of search results, and follows up with alerts and updates as needed.
- Librarians are co-authors on SR collaborations.

ESTIMATED TIMELINE (8-16 WEEKS)

1. Conduct a preliminary search in Ovid's Medline deliver the strategy and results to the team for review (2 Weeks)

2. The team will inform us if there are concepts/terms that might have been overlooked that should be included and/or if the results appear on target. If this search is OK, we will move ahead to the additional databases. We will also deliver the strategy to an EXTERNAL librarian for review and feedback. (1 week)

3. Search teams propose relevant databases and Librarians may suggest others. Librarians search recommended databases (8 Weeks -10 weeks)

LIBRARIAN PRELIMINARY DATABASE RECOMMENDATIONS:

1. Medline
2. EMBASE
3. Cochrane Library
4. CINAHL
5. PsycINFO

4. Deliver results via Covidence

There will probably be a lot of overlap. The Librarian will remove duplicate records and coordinate the EndNote database.

5. Cited and Reference Search -Time frame varies depending on number of articles chosen (2+ weeks)

The team will select the articles for inclusion and send to the Librarians. Using Scopus and/or Web of Science the librarians will conduct a search of the references listed in the bibliographies and an additional search to determine if the inclusion articles have been cited. Deliver results via EndNote.

6. Related articles Search (1 week)

A related articles search in PubMed will be conducted based on the inclusion articles. Deliver results via EndNote.

7. Write literature search methodology (1 week, could be much shorter)

Once the literature search is completed we will write the literature search methodology section for the submitted manuscript

8. Follow up with alerts and updates (if needed) (Ongoing/until submission to publication)

9. Suggest Journals for manuscript submission (optional) (2 days)

Suggestions will include a report with instructions to authors, Impact Factors and indexing information.

Databases Searches and Number of Results

Database	**Dates searched**	**Number of references retrieved**	**Total number after de-duplication**
Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and **Ovid MEDLINE(R)** 1946 to Present	01/25/18	1314	
Embase (Ovid) 1974 to Present	01/25/18	1202	
Cochrane Reviews, part of *The Cochrane Library*.	01/25/18	79	
CINAHL	01/25/18	268	
PsycINFO	01/25/18	463	
Sub-total		3326	
PubMed - related articles and **Scopus** – forward citations		626	
Total after combining and deleting duplicates from subject and related		3956	2373

articles, cited reference & reference & cited reference & reference			

Database Search Strategies

OVID MEDLINE(R) IN-PROCESS & OTHER NON-INDEXED CITATIONS AND OVID MEDLINE(R) 1946 TO PRESENT – JANUARY 25, 2018

1. exp Breast Neoplasms/
2. ((breast or mamma*) adj2 (cancer* or neoplasm* or tumor* or tumour* or mass*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3. exp Developing Countries/
4. ((develop* adj2 (countr* or area*)) or (low* adj1 resource*) or (third adj1 world adj1 countr*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5. exp Africa, Southern/ or exp Africa, Northern/ or exp Africa, Central/ or exp Africa/ or exp Africa, Western/ or exp Africa, Eastern/
6. exp Middle East/
7. exp Asia, Southeastern/ or exp Asia, Northern/ or exp Asia/ or exp Asia, Central/ or exp Asia, Western/
8. (Afghani* or Armenia* or Bangladesh* or Benin or Bhutan or Bolivia* or "Burkina Faso" or Burundi or "Cabo Verde" or Cambodia* or Cameroon or "Central African Republic" or Chad or Comoros or Congo or "Cote d'Ivoire" or Djibouti or Egypt* or "El Salvador" or Eritrea or Ethiopia* or Gambia or Ghana or Guatemala or Guinea or Haiti* or Hondura* or India* or Indonesia* or Kenya* or Kiribati or "North Korea" or Kosovo or Kyrgyz or Lesotho or Liberia* or Madagascar or Malawi or Mali or Mauritania or Micronesia or Moldova or Mongolia* or Morocco or Mozambique or Myanmar or Nepal* or Nicaragua* or Niger* or Pakistan* or "Papua New Guinea" or Philippin* or Rwanda or Samoa or Senegal or "Sierra Leone" or "Solomon Islands" or Somalia* or "South Sudan" or "Sri Lanka" or Sudan or Swaziland or Syria* or Tajikistan or Tanzania or Togo or Tonga or Tunisia* or Uganda* or Ukrain* or Uzbekistan or Vanuatu or Vietnam or Yemen or Zambia or Zimbabwe).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
9. exp Health Knowledge, Attitudes, Practice/
10. exp Social Stigma/
11. exp "Patient Acceptance of Health Care"/
12. (stigma* or (health adj1 (attitude* or knowledg*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol

supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
13. 1 or 2
14. 3 or 4 or 5 or 6 or 7 or 8
15. 9 or 10 or 11 or 12
16. 13 and 14 and 15

THE COCHRANE LIBRARY WILEY - JANUARY 25, 2018

#1 MeSH descriptor: [Breast Neoplasms] explode all trees
#2 ((breast or mamma*) near/2 (cancer* or neoplasm* or tumor* or tumour* or mass*))
#3 MeSH descriptor: [Developing Countries] explode all trees
#4 ((develop* near/2 (countr* or area*)) or (low* near/1 resource*) or (third near/1 world near/1 countr*))
#5 MeSH descriptor: [Africa] explode all trees
#6 MeSH descriptor: [Middle East] explode all trees
#7 MeSH descriptor: [Asia] explode all trees
#8 (Afghani* or Armenia* or Bangladesh* or Benin or Bhutan or Bolivia* or "Burkina Faso" or Burundi or "Cabo Verde" or Cambodia* or Cameroon or "Central African Republic" or Chad or Comoros or Congo or "Cote d'Ivoire" or Djibouti or Egypt* or "El Salvador" or Eritrea or Ethiopia* or Gambia or Ghana or Guatemala or Guinea or Haiti* or Hondura* or India* or Indonesia* or Kenya* or Kiribati or "North Korea" or Kosovo or Kyrgyz or Lesotho or Liberia* or Madagascar or Malawi or Mali or Mauritania or Micronesia or Moldova or Mongolia* or Morocco or Mozambique or Myanmar or Nepal* or Nicaragua* or Niger* or Pakistan* or "Papua New Guinea" or Philippin* or Rwanda or Samoa or Senegal or "Sierra Leone" or "Solomon Islands" or Somalia* or "South Sudan" or "Sri Lanka" or Sudan or Swaziland or Syria* or Tajikistan or Tanzania or Togo or Tonga or Tunisia* or Uganda* or Ukrain* or Uzbekistan or Vanuatu or Vietnam or Yemen or Zambia or Zimbabwe)
#9 MeSH descriptor: [Health Knowledge, Attitudes, Practice] explode all trees
#10 MeSH descriptor: [Social Stigma] explode all trees
#11 MeSH descriptor: [Patient Acceptance of Health Care] explode all trees
#12 (stigma* or (health near/1 (attitude* or knowledg*)))
#13 #1 or #2
#14 #3 or #4 or #5 or #6 or #7 or #8
#15 #9 or #10 or #11 or #12
#16 #13 and #14 and #15

EMBASE (OVID) 1974 TO JANUARY 31, 2014- JANUARY 25, 2018

1. exp breast tumor/
2. ((breast or mamma*) adj2 (cancer* or neoplasm* or tumor* or tumour* or mass*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]

3. exp developing country/
4. ((develop* adj2 (countr* or area*)) or (low* adj1 resource*) or (third adj1 world adj1 countr*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
5. exp "Africa south of the Sahara"/ or exp South Africa/ or exp Africa/ or exp North Africa/ or exp Central Africa/
6. exp Middle East/
7. exp South Asia/ or exp Asia/ or exp Southeast Asia/
8. (Afghani* or Armenia* or Bangladesh* or Benin or Bhutan or Bolivia* or "Burkina Faso" or Burundi or "Cabo Verde" or Cambodia* or Cameroon or "Central African Republic" or Chad or Comoros or Congo or "Cote d'Ivoire" or Djibouti or Egypt* or "El Salvador" or Eritrea or Ethiopia* or Gambia or Ghana or Guatemala or Guinea or Haiti* or Hondura* or India* or Indonesia* or Kenya* or Kiribati or "North Korea" or Kosovo or Kyrgyz or Lesotho or Liberia* or Madagascar or Malawi or Mali or Mauritania or Micronesia or Moldova or Mongolia* or Morocco or Mozambique or Myanmar or Nepal* or Nicaragua* or Niger* or Pakistan* or "Papua New Guinea" or Philippin* or Rwanda or Samoa or Senegal or "Sierra Leone" or "Solomon Islands" or Somalia* or "South Sudan" or "Sri Lanka" or Sudan or Swaziland or Syria* or Tajikistan or Tanzania or Togo or Tonga or Tunisia* or Uganda* or Ukrain* or Uzbekistan or Vanuatu or Vietnam or Yemen or Zambia or Zimbabwe).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
9. exp attitude to health/
10. exp social stigma/
11. exp patient attitude/
12. (stigma* or (health adj2 (attitude* or knowledg*))).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
13. 1 or 2
14. 3 or 4 or 5 or 6 or 7 or 8
15. 9 or 10 or 11 or 12
16. 13 and 14 and 15

CINAHL - JANUARY 25, 2018

S14 S11 AND S12 AND S13
S13 S9 OR S10
S12 S3 OR S4 OR S5 OR S6 OR S7 OR S8
S11 S1 OR S2
S10 (stigma* or (health N1 (attitude* or knowledg*)))
S9 (MH "Stigma")
S8 (Afghani* or Armenia* or Bangladesh* or Benin or Bhutan or Bolivia* or "Burkina Faso" or Burundi or "Cabo Verde" or Cambodia* or Cameroon or "Central African Republic" or Chad or Comoros or Congo or "Cote d'Ivoire" or Djibouti or Egypt* or "El Salvador" or Eritrea or

Ethiopia* or Gambia or Ghana or Guatemala or Guinea or Haiti* or Hondura* or India* or Indonesia* or Kenya* or Kiribati or "North Korea" or Kosovo or Kyrgyz or Lesotho or Liberia* or Madagascar or Malawi or Mali or Mauritania or Mic ...
S7 (MH "Asia+") OR (MH "Asia, Western+") OR (MH "Asia, Southeastern+") OR (MH "Asia, Central+")
S6 (MH "Middle East+")
S5 (MH "Africa+") OR (MH "Africa South of the Sahara+") OR (MH "Africa, Western+") OR (MH "Africa, Southern+") OR (MH "Africa, Northern+") OR (MH "Africa, Eastern+") OR (MH "Africa, Central+")
S4 ((develop* N2 (countr* or area*)) or (low* N1 resource*) or (third N1 world N1 countr*))
S3 (MH "Developing Countries")
S2 ((breast or mamma*) N2 (cancer* or neoplasm* or tumor* or tumour* or mass*))
S1 (MH "Breast Neoplasms+")

PSYCINFO - JANUARY 25, 2018

S9 S1 AND S7 AND S8
S8 S2 OR S3 OR S4 OR S5 OR S6
S7 (stigma* or (health N1 (attitude* or knowledg*)))
S6 (Afghani* or Armenia* or Bangladesh* or Benin or Bhutan or Bolivia* or "Burkina Faso" or Burundi or "Cabo Verde" or Cambodia* or Cameroon or "Central African Republic" or Chad or Comoros or Congo or "Cote d'Ivoire" or Djibouti or Egypt* or "El Salvador" or Eritrea or Ethiopia* or Gambia or Ghana or Guatemala or Guinea or Haiti* or Hondura* or India* or Indonesia* or Kenya* or Kiribati or "North Korea" or Kosovo or Kyrgyz or Lesotho or Liberia* or Madagascar or Malawi or Mali or Mauritania or Mic ...
S5 Asia*
S4 "Middle East"
S3 Africa*
S2 ((develop* N2 (countr* or area*)) or (low* N1 resource*) or (third N1 world N1 countr*))
S1 ((breast or mamma*) N2 (cancer* or neoplasm* or tumor* or tumour* or mass*))

Appendix 3: Data extraction sheet

Variable	Responses
Reviewer	
Title	Free text

Unique Identifier (UI)/PMID Number	Free text
Year of Publication	
Country of Publication	
Journal	
Open Access Journal	Yes/no
Accept /reject Inclusion criteria – addresses: Stigma - Treatment delays - Barriers - Interventions	Accept /Review/Discuss with co-reviewers
If 'Reject' or 'Discuss', please note reasons why	Free text
Introduction:	
Country	Free text
Continent	Asia/Africa/North America/Europe/South America/ Australia/Antartica
Region	South East Asia/East Asia/Central Asia/South West Asia (Middle East)/ West Africa/East Africa/South Africa/North Africa/Central America/South America/Carribean/North Africa
Breast Cancer	Yes/no
Other cancer	Yes /no
List other Type of cancer	Free text
Author i.e. Raza et al, (for authors with multiple papers list first and second authors i.e. Bannon, hanning et al)	Free text
Study type	Qualitative/Quantitative/Mixed methods
Qualitative Study design/instruments	Structured Interview / Semi- structured interview/ Focus groups/Community meetings/Cross-sectional study /
Quantitative Study design/instruments –Tick all that apply	Cross sectional survey Self-designed questionnaire/ Validated questionnaire
Multiple samples	Yes/No
Sample Population and size 1.Breast cancer patients with early disease 2. breast cancer patients with advanced disease 3. Breast cancer survivors 4. Women attending clinic 5. Women in the community 6. Men in the community 7. Spouses of breast cancer patients 8. Caregivers of breast cancer patients(relatives) 9.Nurses 10.Doctors	Indicate numbers of each sample population: Free text

11. Others -specify	
Range of population ages (indicate if not given)	Free text
Mean of population age (indicate if not given)	Free text
Population characteristics Indicate distribution in Sample population	Married ----, Single…….Divorced……Widowed….
No of children (means if listed)	Free text
Study setting	Urban/ rural/ Semi-urban/unknown
Stage of cancer of participants mentioned	Yes/No/Mentioned
If listed numbers and percentages of patients with stage 3 and 4	Free text
Treatment listed	Yes/No/Not mentioned
Treatments given to population	Surgery/Chemotherapy/Radiation Therapy
Sample population completed treatment	Yes/ No/Not mentioned
Country has national insurance scheme	Yes/No/Not mentioned
Population has access to screening for breast cancer	Yes/no/Not mentioned
Distance from health facility given	Yes/no/not mentioned (explain if given)
Are any delays defined/reported?	Yes / no / unsure____
What was the primary outcome measure and what were the results?	Free text
Barriers	
Stigma reported?	Yes/no/unsure___
Type of stigma	1. Experienced (stigma that is enacted through interpersonal acts of discrimination) 2. Perceived (perception of the prevalence of stigmatizing attitudes in the community or among other groups(e.g health care providers) 3. Anticipated (Fear of stigma whether or not it is actually experienced) 4. Secondary (sigma by association, extended to family or other care givers of stigmatized individuals) 5. Observed (stigma occurring to others that is witnessed or observed) 6. Layered (the intersecting of stigmas faced by individuals who are part of multiple marginalized groups)
Qualitative findings/Themes	Free Text
Other barriers reported	Yes/no/unsure
Type of barriers reported	1. Financial factors – No money to pay for treatment

(tick all that apply)	2. Logistical (no time to access health care/ no one to take the to hospital for treatment/looking after others) 3. Poor cancer awareness (Lack of knowledge of breast cancer and risk factors) 4. Poor access to diagnostics 5. Inaccurate clinical assessment misdiagnosis 6. poor referral pathways 7. Geographical barriers 8. Sociocultural factors 9. Other…….explain
Other social cultural factors	Yes/no/unsure
If yes for socio-cultural reasons. Tick all that apply	1. Fatalism (belief that death is inevitable for all cancer patients so why seek treatment) 2. Conservatism/modesty (Shy/embarrassed to be examined by anyone male) 3. Collectivism (decisions made as a community not as an individual) 4. Use of complementary alternative medicine 5. Fear of Surgery/Mastectomy 6. Myths/beliefs around cancer – e.g. caused by evil eye 7. Religious beliefs as a barrier
Interventions	
Any interventions to decrease stigma addressed?	Yes / no / unsure___
Which intervention(s) reported	Community engagement/Improving health literacy/Improving access to primary care Improving primary care provider capacity/educating health workers/Providing supportive counselling and care Increasing availability of treatment/Addressing financial issues/Improving communication and engagement
Was intervention reported as successful/efficacious	Yes / no / not studied or reported
What outcome measure was used to report the intervention success?	Time interval / stage of disease / treatment access / other Duration of interval: (decrease in days) Stage of disease: (decrease in advanced stage) Treatment access: (number of cancer patients accessing care) Other: ()
Were recommendations given	Yes/ no/unsure
What recommendations given	Free text
Quality assessment	
Rate study in terms of bias- Qualsyst, COREQ	N/A or yes (2) Partial (1) or No (1)
Justify reason	Free text

Appendix 4:

QualSyst scoring criteria for assessing study quality of studies:

Checklist for assessing the quality of quantitative studies

Criteria

1. Question / objective sufficiently described?

2. Study design evident and appropriate?

3. Method of subject/comparison group selection or source of information/input variables described and appropriate?

4. Subject (and comparison group, if applicable) characteristics sufficiently described?

5. If interventional and random allocation was possible, was it described?

6. If interventional and blinding of investigators was possible, was it reported?

7. If interventional and blinding of subjects was possible, was it reported?

8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?

9 Sample size appropriate?

10. Analytic methods described/justified and appropriate?

11. Some estimate of variance is reported for the main results? 12. Controlled for confounding? 13. Results reported in sufficient detail? 14. Conclusions supported by the results?

Scoring: YES (2) PARTIAL(1) NO(0) N/A

Appendix 5: COREQ method for scoring

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

COREQ 32 item scoring system.

APPENDIX 6:

SUMMARY OF REVIEW STUDIES

	Author	Study Title	Study Type	Year of Publication	Publisher
1	Al Dasoqi et al.	Screening for breast cancer among young Jordanian women: ambiguity and apprehension.	Qualitative	2013	International Nursing Review
2	Alqaissi, N.M. et al.	Exploring common meanings of social support as experienced by Jordanian women with breast cancer.	Qualitative	2010	Cancer Nursing
3	Asobayire, A et al.	Women's cultural perceptions and attitudes towards breast cancer: Northern Ghana.	Qualitative	2015	Health Promotion International
4	Aziato, L et al.	Breast Cancer Diagnosis and Factors Influencing Treatment Decisions in Ghana.	Qualitative	2015	Health Care for Women International
5	Banning M et al.	Perceptions of breast health practices in Pakistani Muslim women.	Mixed Methods	2009	Asian Pacific Journal of Cancer Prevention
6	Banning, M et al.	Managing the illness experience of women with advanced breast cancer: hopes and fears of cancer-related insecurity.	Qualitative	2013	European Journal of Cancer Care
7	Banning, M et al.	The impact of culture and sociological and psychological issues on Muslim patients with breast cancer in Pakistan.	Qualitative	2009	Cancer Nursing
8	De Ver Dye, T et al.	A mixed-method assessment of beliefs and practice around breast cancer in Ethiopia: implications for public health programming and cancer control.	Mixed Methods	2011	Global Public Health
9	Dey, S et al.	Breast Cancer Awareness and Prevention Behavior Among Women of Delhi, India: Identifying Barriers to Early Detection.	Qualitative	2016	Breast Cancer: Basic and Clinical Research
10	Doumit, M.A.A. et al.	Living with breast cancer, a Lebanese experience.	Qualitative	2010	European Journal of Oncology Nursing : The Official Journal of European

					Oncology Nursing Society
11	Gunusen N.P. et al.	Experiences of Turkish women with breast cancer during the treatment process and facilitating coping factors.	Qualitative	2013	Asian Pacific Journal of Cancer Prevention
12	Iskandarsyah, A et al.	Psychosocial and cultural reasons for delay in seeking help and nonadherence to treatment in Indonesian women with breast cancer: a qualitative study.	Qualitative	2014	Health psychology: Official Journal of the Division of Health Psychology, American Psychological Association
13	Keshavarz, Z et al.	Factors for performing breast and cervix cancer screening by Iranian female workers: a qualitative-model study.	Qualitative	2011	Asian Pacific Journal of Cancer Prevention
14	Khazaee-Pool, M et al.	Breast cancer-preventive behaviors: exploring Iranian women's experiences.	Qualitative	2014	BMC Women's Health
15	Lim, J.N.W. et al.	Barriers to early presentation of self-discovered breast cancer in Singapore and Malaysia: a qualitative multicentre study.	Qualitative	2015	BMJ Open
16	Maree J.E. et al.	"My experience has been a terrible one, something I could not run away from": Zambian women's experiences of advanced breast cancer.	Qualitative	2015	International Journal of Africa Nursing Sciences
17	McEwan, J et al.	"Injustice! That is the cause": a qualitative study of the social, economic, and structural determinants of late diagnosis and treatment of breast cancer in Egypt.	Qualitative	2014	Cancer Nursing
18	Mdondolo N et al.	Cultural factors associated with the management of breast lumps amongst Xhosa women.	Qualitative	2003	Health SA Gesondheid Sep
19	Meacham, E et al.	Exploring stigma as a barrier to cancer service engagement with breast cancer survivors in Kampala, Uganda.	Qualitative	2016	Psycho-oncology
20	Mena, M et al.	Evaluation of the impact of a breast cancer awareness program in rural Ghana: a cross-sectional survey.	Quantitative	2014	International Journal of Cancer
21	Najmabadi, K.M. et al.	Self-disclosure of breast cancer diagnosis by Iranian women to friends and colleagues.	Quantitative	2014	Asian Pacific Journal of Cancer Prevention

22	Nyblade, L et al.	A qualitative exploration of cervical and breast cancer stigma in Karnataka, India.	Qualitative	2017	BMC Women's Health
23	Obeidat, R.F. et al.	Controlling fear: Jordanian women's perceptions of the diagnosis and surgical treatment of early stage breast cancer.	Qualitative	2012	Cancer Nursing
24	Ohaeri, B.M. et al.	Relationship of knowledge of psychosocial issues about cancer with psychic distress and adjustment among breast cancer clinic attendees in a Nigerian teaching hospital.	Quantitative	2012	Psycho-oncology
25	Ohaeri, J.U. et al.	Psychosocial concerns of Nigerian women with breast and cervical cancer.	Quantitative	1998	Psycho-oncology
26	Opoku, S.Y. et al.	Knowledge, attitudes, beliefs, behaviour and breast cancer screening practices in Ghana, West Africa.	Quantitative	2012	The Pan African Medical Journal
27	Raza, S et al.	Breast cancer in Pakistan: identifying local beliefs and knowledge.	Quantitative	2012	Journal of the American College of Radiology
28	Samson, B et al.	Lived in experience of women with breast cancer.	Qualitative	2016	Asian Journal of Pharmaceutical and Clinical Research
29	Şengün, İ et al.	Experiences of Turkish survivors of breast cancer: Neuman systems model perspective.	Qualitative	2016	Japan Journal of Nursing Science
30	Shaheen, R et al.	Barriers and opportunities for early detection of breast cancer in Gaza women.	Qualitative	2011	The Breast
31	Suwankhong, D et al.	Breast Cancer Treatment: Experiences of Changes and Social Stigma Among Thai Women in Southern Thailand.	Qualitative	2016	Cancer Nursing
32	Taha, H et al.	'Would a man smell a rose then throw it away?' Jordanian men's perspectives on women's breast cancer and breast health.	Qualitative	2013	BMC Women's Health
33	Taha, H et al.	"Voices of fear and safety" women's ambivalence towards breast cancer and breast health: a qualitative study from Jordan.	Qualitative	2012	BMC Women's Health
34	Taib, N.A. et al	Recognising symptoms of breast cancer as a reason for	Qualitative	2011	Asian Pacific Journal of

		delayed presentation in Asian women--the psycho-socio-cultural model for breast symptom appraisal: opportunities for intervention.			Cancer Prevention
35	Taleghani F. et al.	Coping with breast cancer in newly diagnosed Iranian women.	Qualitative	2006	Journal of Advanced Nursing
36	Tripathi, L et al.	Stigma Perceived by Women Following Surgery for Breast Cancer.	Quantitative	2017	Indian Journal of Medical and Paediatric Oncology
37	Wigginton, B et al.	Death, contagion and shame: The potential of cancer survivors' advocacy in Zambia.	Qualitative	2018	Health care for Women International
38	Wright, S.V.	An investigation into the causes of absconding among black African breast cancer patients.	Qualitative	1997	South African Medical Journal

APPENDIX 7: ASSOCIATIONS ANALYSIS FOR SYSTEMATIC REVIEW

Table 1. Association between Continent of Study and Stigma/Sociocultural Factor Rates

		Continent		
		Africa	**Asia**	**p-value**
Stigma				
Anticipated	Yes	5 (41.7)	16 (61.5)	0.31
	No	7 (58.3)	10 (38.5)	
Experienced	Yes	4 (33.3)	7 (26.9)	0.71
	No	8 (66.7)	19 (73.1)	
Layered	Yes	2 (16.7)	1 (3.8)	0.23
	No	10 (83.3)	25 (96.2)	
Perceived	Yes	8 (66.7)	13 (50)	0.49
	No	4 (33.3)	13 (50)	
Secondary	Yes	2 (16.7)	6 (23.1)	>0.95
	No	10 (83.3)	20 (76.9)	
Sociocultural Factors				
Collectivism	Yes	1 (8.3)	1 (3.8)	0.54
	No	11 (91.7)	25 (96.2)	
Alternative Medicine	Yes	7 (58.3)	4 (15.4)	**0.017**
	No	5 (41.7)	22 (84.6)	
Fatalism	Yes	8 (66.7)	17 (65.4)	>0.95
	No	4 (33.3)	9 (34.6)	
Myths	Yes	9 (75)	9 (34.6)	**0.035**
	No	3 (25)	17 (65.4)	
Religious	Yes	2 (16.7)	7 (26.9)	0.69
	No	10 (83.3)	19 (73.1)	
Fear of Surgery	Yes	7 (58.3)	8 (30.8)	0.16
	No	5 (41.7)	18 (69.2)	

Synopsis:

This table presents the comparison of stigma and sociocultural factor rates between the two continents. No significant differences in stigma rates were noted between Asian countries and African countries (p=0.23->0.95). However, studies from Africa reported higher rates of alternative medicine use (58%, 7/12) compared to studies from Asia (15%, 4/26), p=0.017. Additionally, studies from Africa reported higher rates of myths (75%, 9/12) compared to Asian studies (35%, 9/26), p=0.035. No other significant differences were noted in sociocultural factors (p=0.16->0.95).

Table 2. Association between Region of Study and Stigma/Sociocultural Factor Rates

		Region		
		Middle East and India	**Other**	**p-value**
Stigma				
Anticipated	Yes	13 (56.5)	8 (53.3)	>0.95
	No	10 (43.5)	7 (46.7)	
Experienced	Yes	7 (30.4)	4 (26.7)	>0.95
	No	16 (69.6)	11 (73.3)	
Layered	Yes	1 (4.3)	2 (13.3)	0.55
	No	22 (95.7)	13 (86.7)	
Perceived	Yes	11 (47.8)	10 (66.7)	0.33
	No	12 (52.2)	5 (33.3)	
Secondary	Yes	5 (21.7)	3 (20)	>0.95
	No	18 (78.3)	12 (80)	
Sociocultural Factors				
Collectivism	Yes	1 (4.3)	1 (6.7)	>0.95
	No	22 (95.7)	14 (93.3)	
Alternative Medicine	Yes	2 (8.7)	9 (60)	**0.001**
	No	21 (91.3)	6 (40)	
Fatalism	Yes	15 (65.2)	10 (66.7)	>0.95
	No	8 (34.8)	5 (33.3)	
Myths	Yes	9 (39.1)	9 (60)	0.32
	No	14 (60.9)	6 (40)	
Religious	Yes	7 (30.4)	2 (13.3)	0.27
	No	16 (69.6)	13 (86.7)	
Fear of Surgery	Yes	6 (26.1)	9 (60)	**0.049**
	No	17 (73.9)	6 (40)	

Synopsis

- This table presents the stigma and sociocultural factor proportions by region. Other countries include all those in West, East, and South Africa and East Asian countries. Similar to the continent breakdown, no significant differences in stigma were noted (p=0.33->0.95), and alternative medicine rates were higher in other countries (60%, 9/15) compared to the Middle Eastern countries and India (9%, 2/23), p=0.001. Additionally, fear of surgery was marginally higher in other countries (60%, 9/15) compared to Middle Eastern countries and India (26%, 6/23), p=0.049. No significant differences in myth rates (p=0.32) or other sociocultural factors were found (p=0.27->0.95).

Table 3. Association between Rural Study Participants and Stigma/Sociocultural Factor Rates

		Rural Study Participants		
		No Rural Sample	Rural Sample	p-value
Stigma				
Anticipated	Yes	11 (57.9)	4 (33.3)	0.27
	No	8 (42.1)	8 (66.7)	
Experienced	Yes	6 (31.6)	3 (25)	>0.95
	No	13 (68.4)	9 (75)	
Layered	Yes	2 (10.5)	1 (8.3)	>0.95
	No	17 (89.5)	11 (91.7)	
Perceived	Yes	11 (57.9)	8 (66.7)	0.72
	No	8 (42.1)	4 (33.3)	
Secondary	Yes	4 (21.1)	3 (25)	>0.95
	No	15 (78.9)	9 (75)	
Sociocultural Factors				
Collectivism	Yes	2 (10.5)	0 (0)	0.51
	No	17 (89.5)	12 (100)	
Alternative Medicine	Yes	8 (42.1)	2 (16.7)	0.24
	No	11 (57.9)	10 (83.3)	
Fatalism	Yes	15 (78.9)	6 (50)	0.13
	No	4 (21.1)	6 (50)	
Myths	Yes	11 (57.9)	6 (50)	0.72
	No	8 (42.1)	6 (50)	
Religious	Yes	5 (26.3)	2 (16.7)	0.68
	No	14 (73.7)	10 (83.3)	
Fear of Surgery	Yes	8 (42.1)	7 (58.3)	0.47
	No	11 (57.9)	5 (41.7)	

Synopsis

This table presents the comparison of stigma and sociocultural factor rates between the rural study settings. No significant differences in stigma rates were found between studies that included rural participants and those that did not (p=0.27->0.95). Similarly, no significant differences were found in the rates of sociocultural factors (p=0.13-0.68).

Table 4. Association between Including Breast Cancer Patients and Stigma/Sociocultural Factor Rates

		Breast Cancer Patients Included		
		No	**Yes**	**p-value**
Stigma				
Anticipated	Yes	6 (46.2)	15 (60)	0.50
	No	7 (53.8)	10 (40)	
Experienced	Yes	1 (7.7)	10 (40)	0.060
	No	12 (92.3)	15 (60)	
Layered	Yes	1 (7.7)	2 (8)	>0.95
	No	12 (92.3)	23 (92)	
Perceived	Yes	9 (69.2)	12 (48)	0.31
	No	4 (30.8)	13 (52)	
Secondary	Yes	2 (15.4)	6 (24)	0.69
	No	11 (84.6)	19 (76)	
Sociocultural Factors				
Collectivism	Yes	1 (7.7)	1 (4)	>0.95
	No	12 (92.3)	24 (96)	
Alternative Medicine	Yes	2 (15.4)	9 (36)	0.27
	No	11 (84.6)	16 (64)	
Fatalism	Yes	8 (61.5)	17 (68)	0.73
	No	5 (38.5)	8 (32)	
Myths	Yes	8 (61.5)	10 (40)	0.31
	No	5 (38.5)	15 (60)	
Religious	Yes	6 (46.2)	3 (12)	**0.040**
	No	7 (53.8)	22 (88)	
Fear of Surgery	Yes	6 (46.2)	9 (36)	0.73
	No	7 (53.8)	16 (64)	

Synopsis

This table presents the comparison of stigma and sociocultural factor rates between studies that included breast cancer patients and those that did not. No significant differences in stigma rates were noted between these studies, although experienced stigma approached significance (p=0.060, others p=0.31->0.95). Studies that included breast cancer patients had higher rates of experienced stigma (40%, 10/25) compared to studies that did not include any breast cancer patients (8%, 1/13). Studies that did not include breast cancer patients reported higher rates of religious sociocultural factor (46%, 6/13) compared to studies that included breast cancer patients (12%, 3/25), p=0.040. No other significant differences in sociocultural factors were found (p=0.31->0.95).

Table 5. Association between Publication Year and Stigma/Sociocultural Factor Rates

		Publication Year			
		pre-2010	**2010-2014**	**2014-2018**	**p-value**
Stigma					
Anticipated	Yes	2 (40)	13 (56.5)	6 (60)	0.80
	No	3 (60)	10 (43.5)	4 (40)	
Experienced	Yes	2 (40)	5 (21.7)	4 (40)	0.51
	No	3 (60)	18 (78.3)	6 (60)	
Layered	Yes	1 (20)	1 (4.3)	1 (10)	0.34
	No	4 (80)	22 (95.7)	9 (90)	
Perceived	Yes	4 (80)	10 (43.5)	7 (70)	0.26
	No	1 (20)	13 (56.5)	3 (30)	
Secondary	Yes	0 (0)	5 (21.7)	3 (30)	0.54
	No	5 (100)	18 (78.3)	7 (70)	
Sociocultural Factors					
Collectivism	Yes	1 (20)	1 (4.3)	0 (0)	0.31
	No	4 (80)	22 (95.7)	10 (100)	
Alternative Medicine	Yes	3 (60)	5 (21.7)	3 (30)	0.21
	No	2 (40)	18 (78.3)	7 (70)	
Fatalism	Yes	3 (60)	15 (65.2)	7 (70)	>0.95
	No	2 (40)	8 (34.8)	3 (30)	
Myths	Yes	3 (60)	11 (47.8)	4 (40)	0.81
	No	2 (40)	12 (52.2)	6 (60)	
Religious	Yes	2 (40)	7 (30.4)	0 (0)	0.10
	No	3 (60)	16 (69.6)	10 (100)	
Fear of Surgery	Yes	3 (60)	9 (39.1)	3 (30)	0.51
	No	2 (40)	14 (60.9)	7 (70)	

Synopsis

This table presents the comparison of stigma and sociocultural factor rates by publication year. No significant differences were found in stigma rates (p=0.26-0.80) or sociocultural factors (p=0.10->0.95).

Table 6. Association between Anticipated Stigma and Sociocultural Factor Rates

		Anticipated Stigma		
		No	**Yes**	**p-value**
Sociocultural Factors				
Collectivism	Yes	1 (5.9)	1 (4.8)	>0.95
	No	16 (94.1)	20 (95.2)	
Alternative Medicine	Yes	6 (35.3)	5 (23.8)	0.49
	No	11 (64.7)	16 (76.2)	
Fatalism	Yes	12 (70.6)	13 (61.9)	0.73
	No	5 (29.4)	8 (38.1)	
Myths	Yes	10 (58.8)	8 (38.1)	0.33
	No	7 (41.2)	13 (61.9)	
Religious	Yes	2 (11.8)	7 (33.3)	0.15
	No	15 (88.2)	14 (66.7)	
Fear of Surgery	Yes	6 (35.3)	9 (42.9)	0.74
	No	11 (64.7)	12 (57.1)	

Synopsis

This table presents the relationship between anticipated stigma and sociocultural factors. No significant differences were found between studies that had anticipated stigma and those that did not (p=0.15->0.95).

Table 7. Association between Experienced Stigma and Sociocultural Factor Rates

		Experienced Stigma		
		No	Yes	p-value
Sociocultural Factors				
Collectivism	Yes	2 (7.4)	0 (0)	>0.95
	No	25 (92.6)	11 (100)	
Alternative Medicine	Yes	9 (33.3)	2 (18.2)	0.45
	No	18 (66.7)	9 (81.8)	
Fatalism	Yes	17 (63)	8 (72.7)	0.71
	No	10 (37)	3 (27.3)	
Myths	Yes	13 (48.1)	5 (45.5)	>0.95
	No	14 (51.9)	6 (54.5)	
Religious	Yes	8 (29.6)	1 (9.1)	0.24
	No	19 (70.4)	10 (90.9)	
Fear of Surgery	Yes	11 (40.7)	4 (36.4)	>0.95
	No	16 (59.3)	7 (63.6)	

Synopsis

This table presents the relationship between experienced stigma and sociocultural factors. No significant differences were found between studies that had experienced stigma and those that did not (p=0.24->0.95).

Table 8. Association between Layered Stigma and Sociocultural Factor Rates

		Layered Stigma		
		No	**Yes**	**p-value**
Sociocultural Factors				
Collectivism	Yes	2 (5.7)	0 (0)	>0.95
	No	33 (94.3)	3 (100)	
Alternative Medicine	Yes	9 (25.7)	2 (66.7)	0.20
	No	26 (74.3)	1 (33.3)	
Fatalism	Yes	24 (68.6)	1 (33.3)	0.27
	No	11 (31.4)	2 (66.7)	
Myths	Yes	17 (48.6)	1 (33.3)	>0.95
	No	18 (51.4)	2 (66.7)	
Religious	Yes	8 (22.9)	1 (33.3)	>0.95
	No	27 (77.1)	2 (66.7)	
Fear of Surgery	Yes	13 (37.1)	2 (66.7)	0.55
	No	22 (62.9)	1 (33.3)	

Synopsis

This table presents the relationship between layered stigma and sociocultural factors. No significant differences were found between studies that had layered stigma and those that did not (p=0.20->0.95).

Table 9. Association between Perceived Stigma and Sociocultural Factor Rates

		Perceived Stigma		
		No	**Yes**	**p-value**
Sociocultural Factors				
Collectivism	Yes	0 (0)	2 (9.5)	0.49
	No	17 (100)	19 (90.5)	
Alternative Medicine	Yes	1 (5.9)	10 (47.6)	**0.010**
	No	16 (94.1)	11 (52.4)	
Fatalism	Yes	10 (58.8)	15 (71.4)	0.50
	No	7 (41.2)	6 (28.6)	
Myths	Yes	6 (35.3)	12 (57.1)	0.21
	No	11 (64.7)	9 (42.9)	
Religious	Yes	3 (17.6)	6 (28.6)	0.48
	No	14 (82.4)	15 (71.4)	
Fear of Surgery	Yes	5 (29.4)	10 (47.6)	0.33
	No	12 (70.6)	11 (52.4)	

Synopsis

This table presents the relationship between perceived stigma and sociocultural factors. Studies that had perceived stigma had higher rates of alternative medicine use (48%, 10/21) than studies that did not have perceived stigma (6%, 1/17). No other significant differences were found between studies that had perceived stigma and those that did not (p=0.21->0.95).

Table 10. Association between Secondary Stigma and Sociocultural Factor Rates

		Secondary Stigma		
		No	**Yes**	**p-value**
Sociocultural Factors				
Collectivism	Yes	2 (6.7)	0 (0)	>0.95
	No	28 (93.3)	8 (100)	
Alternative Medicine	Yes	9 (30)	2 (25)	>0.95
	No	21 (70)	6 (75)	
Fatalism	Yes	18 (60)	7 (87.5)	0.22
	No	12 (40)	1 (12.5)	
Myths	Yes	15 (50)	3 (37.5)	0.70
	No	15 (50)	5 (62.5)	
Religious	Yes	8 (26.7)	1 (12.5)	0.65
	No	22 (73.3)	7 (87.5)	
Fear of Surgery	Yes	12 (40)	3 (37.5)	>0.95
	No	18 (60)	5 (62.5)	

Synopsis

This table presents the relationship between secondary stigma and sociocultural factors. No significant differences were found between studies that had secondary stigma and those that did not (p=0.22->0.95).